Women’s Health: What Women Really Know About Their Own Health
page 20

Getting Out of the Rut: Finding Financial Security
page 17

Making Music with Trevor Martin
page 31
EXECUTIVE CORNER

Dear Friends,

Oh, what a year 2020 has been! As we reflect on the hardships and stress this year has brought, I’d encourage you to also find space for gratitude. I know for myself this year has brought uncertainty and chaos, but also time to slow down and enjoy the little things that I might have otherwise missed. Switching many community events to the virtual setting has been challenging, but I know HFA and our member organizations have found creative ways to still support and bring joy to our community and I’m so grateful for that!

This issue features results of a survey on women’s perspectives. For me, as a woman with a bleeding disorder, it can be challenging and feel as if we are supposed to have all the answers. In such an uncertain world it can feel as if we are supposed to have the answers for our families and friends, and give support when we may not have much to give. It can also feel as if we are supposed to have all the knowledge and wisdom about our health, except sometimes there aren’t many good options that fit your needs.

Know that HFA is here for you. Our programs aim to provide spaces of vulnerability and safety to unpack the hard questions and acknowledge that we do not have all the answers. And our advocacy aims to bring more awareness around access and treatment that women face. Our patient-centered research aims to help bring knowledge and tools so that women can be better supported.

We’re here for all of you during this challenging time. Here’s to 2020 and hoping for a better 2021!

Allie Ritcey
Board Chair

EXECUTIVE LEADERSHIP
Board Chair • Allie Ritcey
President & CEO • Dr. Sharon Meyers, CFRE

PRODUCTION TEAM
Editor • Emily Roush-Bobolz
Art Direction • Michael DeGrandpre
Design & Layout • Ashley Williams
Copy Editor • Kit Salisbury
Informative Communications Manager • Kyle McKendall

Contributing Writers:
DeBran Tarver, Ph.D., M.P.H., HFA Staff
Emily Roush-Bobolz, HFA Staff
Janet Chupka, R.N., BSN, HFA Staff
Allison Harrison, M.S.W., HFA Staff

Contributing Photographers:
Michael DeGrandpre, Gina Richards

IN THIS ISSUE

What’s the Risk?
Did you know anyone with a bleeding disorders is at risk of developing an inhibitor? Learn how more education about inhibitors is informing the community.

Ending the Cycle
HFA develops education to help the community end the cycle of financial struggle.

Women’s Health
A look at what we learned during a survey with participants of HFA’s Blood Sisterhood and Families programs.

Trevor Martin
Singer-songwriter with hemophilia joins hemophilia dad and music producer to bring music to the world.

Happening Highlights
The latest information and resources for the bleeding disorders community.

Research Portal
Researchers in the bleeding disorders community recently presented their findings at HFA’s Virtual Symposium. Symposium attendees voted on their favorite research posters — meet the winners!

SPECIAL FEATURES

What’s the Risk?
Did you know anyone with a bleeding disorders is at risk of developing an inhibitor? Learn how more education about inhibitors is informing the community.

Ending the Cycle
HFA develops education to help the community end the cycle of financial struggle.

Women’s Health
A look at what we learned during a survey with participants of HFA’s Blood Sisterhood and Families programs.

Trevor Martin
Singer-songwriter with hemophilia joins hemophilia dad and music producer to bring music to the world.

Happening Highlights
The latest information and resources for the bleeding disorders community.

Research Portal
Researchers in the bleeding disorders community recently presented their findings at HFA’s Virtual Symposium. Symposium attendees voted on their favorite research posters — meet the winners!

Inspiring Impact
Learn all the ways to give back.

ON THE COVER:
Hemophilia Federation of America surveyed Blood Sisterhood and Families program participants, like Britnee Vieira who has vWD, to better understand knowledge and awareness of bleeding disorders in women. We break down the results of the survey and what we discovered. Read more on page 20.
The Fun of the Summer Camp Experience Found Online

While bleeding disorders families across the country may have missed the summer ritual of camp due to pandemic restrictions, Hemophilia Federation of America partnered with Beyond Recreation on a three-part webinar series, A Taste of Camp. The virtual camp experience features songs, skits, campfires and fun right at home. Camp directors, camp staff and former campers share ways to prepare children to get the most out of the camp experience.

Find the series in the A Taste of Camp series playlist at www.youtube.com/HemophiliaFederationofAmerica.

Learning to Parent in a Whole New World

An unexpected side effect of the pandemic has been struggles (and wins!) in parenting. A Whole New World: Parenting in a Pandemic is a three-part webinar series featuring Dr. Juliana Bloom, a licensed psychologist and pediatric neuropsychologist. In these webinars, Dr. Bloom discusses parenting during a pandemic with topics specific to age, whether newborns to preschoolers, school-aged children or adolescents, teens and young adults. Dr. Bloom also shares valuable resources for parents to access.

Find the series in the Whole New World playlist at www.youtube.com/HemophiliaFederationofAmerica.

World Federation of Hemophilia Publishes Third Edition of Guidelines

The third edition of the World Federation of Hemophilia Guidelines for the Management of Hemophilia features up-to-date guidance and practical recommendations on the diagnosis and management of hemophilia, including the management of musculoskeletal complications and inhibitors, updates to laboratory diagnosis and genetic assessments and new recommendations on outcome assessments. Led by Dr. Alok Srivastava and Dr. Glenn Pierce Ph.D., WFH Vice President-Medical, WFH says the guidelines come from evidence and is supplemented with expert opinion and patient preference, including more than 300 practical recommendations developed by consensus using the “Trustworthy Consensus-Based Statement” process to ensure reliable guidance. The guide is meant to bridge the gap between treatment practices and care around the world.


Natural Disasters Do Not Discriminate

Hemophilia Federation of America has established the Disaster Relief Fund for community members displaced or impacted by a natural disaster and in need of immediate financial relief. Dealing with wildfires, earthquakes or other natural disasters is challenging for anyone but when someone has a bleeding disorder, it presents an entirely more complicated scenario. Our community has a long history of rallying around families in need and this fund, originally founded in 2017 as a response to the nation’s unprecedented number of national disasters taking place, expands upon our legacy of helping bleeding disorders community members experiencing financial hardship during a time of crisis.

Learn more, apply or make a donation to the fund at www.hemophiliafed.org/disasterrelief.

Sangre Latina Program Hosts Monthly Talks for Spanish-Speaking Community

Once a month Hemophilia Federation of America will host a virtual chat to help the Spanish-speaking bleeding disorders community stay connected during a health emergency. The informal conversations allow attendees to discuss difficult situation many are experiencing. Attendees are encouraged to share stories and techniques on how to deal with the situation.

Register for the monthly chat at bit.ly/HFAHablandoContigo.
Each year, Hemophilia Federation of America awards scholarships to promising students in the bleeding disorders community seeking post-secondary education at a college, university or trade school. We are pleased to award scholarships to the following students.

**Olivia Hoff**
Attending Saint Mary’s College in Notre Dame, Indiana

I am very appreciative to be selected as a scholarship recipient from the Hemophilia Federation of America. The scholarship will allow me to complete my last year of schooling at Saint Mary’s College. I will receive a Bachelor of Science. I am majoring in biology with a minor in chemistry. After graduation I plan to attend medical school in hopes to become a pediatric hematologist. Living with a bleeding disorder and seeing the positive impact my own hematologist has made on my journey, has sparked my long-term career choice. I am very appreciative of accepting this scholarship!

**Olivia Waldenburg**
Attending Spokane Falls Community College in Spokane, Wash.

I am so excited and grateful to be receiving this scholarship from the Hemophilia Federation of America. It means a lot to be receiving a scholarship that hits so close to home. The support of the HFA has allowed me to attend the Spokane Falls Community College and transfer to the University of Montana during the winter semester with a major in business management. My goal is to become a business owner and help other people just as people have helped me through my struggles and challenges. My blood condition has helped shape me into the person I am today and am excited to see where the future takes me. I feel so grateful to be included in this organization.

**Olivia Hoff**
Attending Saint Mary’s College in Notre Dame, Indiana

I am very appreciative to be selected as a scholarship recipient from the Hemophilia Federation of America. The scholarship will allow me to complete my last year of schooling at Saint Mary’s College. I will receive a Bachelor of Science. I am majoring in biology with a minor in chemistry. After graduation I plan to attend medical school in hopes to become a pediatric hematologist. Living with a bleeding disorder and seeing the positive impact my own hematologist has made on my journey, has sparked my long-term career choice. I am very appreciative of accepting this scholarship!

**Olivia Waldenburg**
Attending Spokane Falls Community College in Spokane, Wash.

I am so excited and grateful to be receiving this scholarship from the Hemophilia Federation of America. It means a lot to be receiving a scholarship that hits so close to home. The support of the HFA has allowed me to attend the Spokane Falls Community College and transfer to the University of Montana during the winter semester with a major in business management. My goal is to become a business owner and help other people just as people have helped me through my struggles and challenges. My blood condition has helped shape me into the person I am today and am excited to see where the future takes me. I feel so grateful to be included in this organization.

**Lauren Surbrook**
Attending University of North Carolina Wilmington in Wilmington, N.C.

I am so grateful to be a recipient of a scholarship from the Hemophilia Federation of America. This scholarship is going towards my tuition at the University of North Carolina at Wilmington. I will be finishing my bachelor’s degree in Business Administration with a concentration in Accountancy in May of 2021. I plan to continue my education with a master’s degree and become a CPA. In high school, I was not sure what to expect from the future. I had been hospitalized for a blood disorder condition that my family was unaware that ran in the family. Even though it was slow and took some time, I was so lucky to have an amazing health team to help me recover. Even though it was a painful experience, I am thankful that it happened. We learned that both of my bothers also had the same blood disorder condition. I have come so far since that time in my life. With this opportunity that HFA has given me, it will grant me the chance to continue to make strides towards a brighter future.

**Johan Diaz**
Attending University of Southern California in Los Angeles

It is such an honor to be a recipient of the Hemophilia Federation of America scholarship. The funds from this award will be directly sent to my school, the University of Southern California. Being selected to be awarded this scholarship not only helps support me financially, but also mentally. Funding my education will be one less thing to worry about because of this award. I will be majoring in biomedical engineering with a pre-med emphasis. I chose this field of engineering not only to focus on preparing myself for medical school, but to be able to earn a degree that could secure me a stable job, given that medical school turns out to not be right for me. This field of engineering still helps many people with medical issues, by providing prosthetics and devices for different parts of the human body. I always dreamt of helping people with medical complications because I always looked up to the medical professionals that took care of me. My education has always been my number one priority because I could never have a career in athletics, due to my blood disorder. Yet, my hemophilia has been a blessing in disguise because it has led me to graduate high school with honors and got me into one of the best private schools in the nation.

Congratulations!
The Research Team at Hemophilia Federation of America would like to thank all the wonderful presenters who chose to share their research during HFA’s Annual Symposium Poster Session at the 2020 virtual Symposium in August, as well as all those who visited the first-ever virtual poster session, voting for their favorite posters. Here are some words from our People’s Choice winners about why they do the work they do:

FIRST PLACE
Gender Differences in Parenting Stress and Social Support Among Hemophilia Families
Presented by Carletha Gates, Ph.D., HS-BCP

I am honored to once again be awarded the People’s Choice award for HFA’s annual symposium research poster session. It means a lot to be recognized for the work I hold so near and dear to my heart. I am also elated that HFA has begun to expand their research efforts, giving a platform for researchers to expose the bleeding disorders community to the many studies that exist that are of benefit for our community, particularly those in the psychosocial discipline. My research study on parenting stress and social support was a true labor of love. As a hemophilia mother of four affected children, I know from first-hand experience that parenting stress and having appropriate support is a real concern for parents as they face the many challenges of raising a child with hemophilia. Hemophilia not only concerns the affected child, but the entire family unit, particularly the parents. The main goal of my research was to raise awareness of gender differences related to hemophilia patients’ parental stress and how they can better utilize social support networks as they raise their chronically ill children. Understanding the link among gender, stress, and perceptions of social support is important to help parents develop coping strategies to meet the unique challenges of caring for their children with hemophilia.

My research concluded that all hemophilia parents experience some level of stress and there is a need for gender-specific social support regardless of the child’s hemophilia severity. There is also a need for more in-depth dialogue about the seriousness of parenting stress. Parents need to be engaged in programs and services that can help decrease their stress levels and increase social support use to improve the health, wellness, and overall quality of life of the hemophilia family.

When it comes to your hemophilia A treatment:

Move beyond the threshold® Esperoct® can give you high factor levels for longer.®

Flexible on the go
The ONLY extended half-life product that can be stored up to 104°F!®

Extends half-life beyond the standard 22-hour average half-life in adults®

Switching made easy
with a standard 50 IU/kg dose every 4 days
-50% fewer infusions if you previously infused every other day
-40% fewer infusions if you previously infused 3x a week

High factor levels
At or above 3% for 100% of the time®
At or above 5% for 90% of the time®

Safety Proven across 5 studies, the largest and longest EHL clinical trial program

- Of 1% through factor levels for standard half-life (SHL) products in adults and adolescents.
- Compared with SHL products.
- Data shown are from 42 adults who received a pharmacokinetic (PK) assessment around the first Esperoct® 50 IU/kg dose.
- Pre-dose factor activity (trough) levels were evaluated at follow-up visits. Mean trough levels for adolescents (12–18 years) were 2.7 IU/dL.
- Steady-state FVIII activity levels were estimated in 143 adults and adolescents using pharmacokinetic modeling.
- For up to 3 months.

For Adults and Adolescents

What is Esperoct®?
Esperoct® [antihemophilic factor (recombinant), glycopegylated-exel] is an injectable medicine to treat and prevent or reduce the number of bleeding episodes in people with hemophilia A.

Your healthcare provider may give you Esperoct® when you have surgery
- Esperoct® is not used to treat von Willebrand Disease

IMPORTANT SAFETY INFORMATION

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

What is the most important information I need to know about Esperoct®?
- Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center
- Call your healthcare provider right away if you get any signs of an allergic reaction, such as: hives, chest tightness, wheezing, dizziness, difficulty breathing, and/or swelling of the face

What should I tell my healthcare provider before using Esperoct®?
- Before taking Esperoct®, 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 Esperoct®, which may stop Esperoct® from working properly.

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

What are the possible side effects of Esperoct®?
- Common side effects of Esperoct® include rash or itching, and swelling, pain, rash or redness at the location of infusion

Please see Brief Summary of Prescribing Information on the following page.

Discover more at Esperoct.com.

Esperoct® antihemophilic factor (recombinant), glycopegylated-exel

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

Novo Nordisk is a registered trademark of Novo Nordisk A/S.

©2020 Novo Nordisk. Printed in the USA. US2020SP00014 February 2020

Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.

Extend half-life beyond the standard 22-hour average half-life in adults®

Flexible on the go
The ONLY extended half-life product that can be stored up to 104°F!®

Please see Brief Summary for complete storage instructions.

Discover more at Esperoct.com.

Esperoct® antihemophilic factor (recombinant), glycopegylated-exel

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

Novo Nordisk is a registered trademark of Novo Nordisk A/S.

©2020 Novo Nordisk. Printed in the USA. US2020SP00014 February 2020

Access to research allows researchers and the bleeding disorders community to better understand each other
Use ESPEROCT®? 

Tell your healthcare provider if you are pregnant or planning to become pregnant. 

If you are not sure, talk to your healthcare provider or pharmacist before using this medicine. 

Do not use ESPEROCT® for a condition for which it was not prescribed. Do not share ESPEROCT® with other people, even if they have the same condition. 

Other side effects: 

Common side effects include: 

• rash or itching 

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

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

Released: 10/2019 

ESPEROCT® is a trademark of Novo Nordisk A/S. 

More detailed information is available upon request. 

For information about: 

www.hemophilia.org/research 

For more information about ESPEROCT®, call 1-800-727-6500. 

To view all the posters and their abstracts, visit www.hemophilia.org/research.
HFA develops an inhibitor education initiative to address findings of a survey of patient and caregiver awareness of inhibitors

DEBRAN TARVER, PH.D., STAFF WRITER

People with hemophilia or von Willebrand disease type three, who treat with clotting factor concentrates, are at risk for developing an inhibitor. Inhibitor development makes it more difficult to treat bleeds. It is a serious and costly medical complication.

Hemophilia Federation of America has an opportunity for the bleeding disorders community to learn more about inhibitor development, testing and treatment through our free, online learning platform, Learning Central. The following provides a brief overview of how the inhibitor courses were developed and what participants can expect to see during their Learning Central experience.

WHAT WE LEARNED
Based on findings from a survey of men enrolled in Blood Brotherhood and caregivers in the Families Programs, HFA concluded that additional education was needed for individuals to be able to be able to identify if they or their child are at risk for an inhibitor and if so to:

• Correctly identify the inhibitor testing method name
• Correctly identify all the risk factors for inhibitor development
• Promote individuals at risk to get tested for an inhibitor
• Encourage provider-patient conversations surrounding inhibitor development and testing

As a result, HFA designed the inhibitors courses in Learning Central to increase knowledge and awareness about the signs, symptoms, risk factors and testing for inhibitors for people at risk.

LEARNING CENTRAL DEVELOPMENT
The primary initiative was to develop and launch an educational course including the following topics:

• Inhibitor Basics
• Risk Factors for Developing an Inhibitor
• Signs and Symptoms of Inhibitors
• Testing and Diagnosis of Inhibitors
• Treatment of Inhibitors
• Quality of Life with Inhibitors

HFA partnered with advisors from the Centers for Disease Control and Prevention, a learning technologies firm, a hematologist and a hematologist nurse in the bleeding disorders community to shape content into a digitally interactive and memorable learning experience.

Each topic includes the following:

- Guide: A member of the HFA Community who guides the learner through clinical content, so the learner feels as though they are learning from a friend.
- Show what you know: An opportunity for participants to assess their knowledge at the beginning of each topic.
- Content: Information addressing the topic (e.g., treatment of inhibitors). With guidance from our partner learning designers, hematologists, and CDC. Our goal was to display factual information in clear, and interactive ways.
- Knowledge Check: An opportunity for participants to assess their knowledge at the end of each topic.
- Summary: A brief description of what was discussed and available resources for more information.

The courses also include a series of videos highlighting community members’ experiences with inhibitor signs and symptoms, testing, diagnosis, treatment and quality of life. These videos were developed with the intention of increasing awareness and knowledge of inhibitors from the direct voices of community members who have experienced inhibitors first-hand. The videos address the challenges of living with inhibitors and the importance of being knowledgeable about the content provided in Learning Central. Being knowledgeable about inhibitors allowed these community members to be able to advocate for their, or their family member’s, health and get the needed support from providers.

A LOOK INTO LEARNING DEVELOPMENT
An example of content presented in the courses is an examination of myths related to inhibitors. Some of the myths dispelled are:

MYTH: You can only develop an inhibitor as a baby.

FACT: An inhibitor typically occurs within the first 30 to 50 exposures to factor treatment, so those who are severe or bleed often tend to get diagnosed very young. However, for those who infuse less frequently, it can happen much later in life.

MYTH: Only those with severe hemophilia will develop an inhibitor.

FACT: While inhibitors develop more often among those with severe hemophilia, anyone who infuses clotting factor can develop inhibitors, even those with mild or moderate hemophilia.

MYTH: Product switching causes inhibitors.

FACT: Switching from one clotting factor product to another does not cause or increase your risk of developing an inhibitor.
There was a year during his second-grade year that he was bound to a wheelchair because of his joint issues—a bleed that just didn’t seem to ever get resolved in his knee. And so he was out of school more than he was in school that year and it proved to be very difficult for him and the entire family. But the inhibitor truly did get some of the best of my son and our family at times in those early years when he was in second and third grade.

— Caizandra, mom of son with hemophilia and inhibitors

A setback for the bypassing agent we would use is that the life span (half-life) of it is only two hours and regardless of how much you stack it up, if you combine and give him two doses to what the physician would consider 100%, he’s still only getting coverage for two hours, not an extended 6 hours. You can’t extend it when it’s (half) life is only two hours. So, we’re giving him more, but it’s only lasting two hours. So, if he did have bleeds, we would be infusing every two hours. It puts time constraints on social activities, time constraints on getting him to school, getting to work, practically having a life outside of our infusion schedule.

— Marquita, mom of son with hemophilia and inhibitors

My inhibitor has certainly impacted my work. I found a job where I can work from home which I think for me is essential… Even as someone that works from home, there are days when I can’t even do that because of a bleed and so I use a lot of sick time and I have to write a lot of emails to my co-workers saying I’m really sorry, but I won’t be able to get to this today and maybe not tomorrow either because I have a really bad bleed going on…It’s the single biggest influence on my work life.

— Michael, adult male with hemophilia and inhibitors

Prophylaxis with ADVATE prevented bleeds1

The ability of ADVATE to treat or prevent bleeds was evaluated in a clinical study using a standard prophylaxis, pharmacokinetic driven prophylaxis, and on-demand treatment. 53 previously treated patients (PTPs) with severe to moderately severe hemophilia A were analyzed. For the first 6 months of the study, patients received on-demand treatment. For the following 12 months of the study, patients received either standard prophylaxis every 48 hours or a pharmacokinetic driven prophylaxis every 72 hours. The primary goal of the study was to compare annual bleeding rates between those receiving prophylaxis treatment and those receiving treatment on demand. The number of bleeds per year for the 2 prophylaxis regimens were comparable. Those patients experienced a median of 1 overall bleed per year on either prophylaxis treatment vs 44 overall bleeds per year with on-demand treatment.1 This represented a 98% reduction in overall bleeds per year.

• Zero bleeds were reported in 42% of patients (22 out of 53 patients) during 12 months on prophylaxis. Median reduction in number of bleeds compared to those receiving no prophylaxis treatment was 98%.

ADVATE Important Information

What is ADVATE?

• ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called “classic” hemophilia).
• ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A. Your healthcare provider (HCP) may give you ADVATE when you have surgery.
• ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis). ADVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADVATE?

Do not use ADVATE if you:

• Are allergic to mice or hamsters.
• Are allergic to any ingredient in ADVATE.

Tell your HCP if you are pregnant or breastfeeding because ADVATE may not be right for you.

What should I tell my HCP before using ADVATE?

Tell your HCP if:

• You have or have had medical problems.
• You take any medicine, including prescription and non prescription medicines, such as over the counter medicines, supplements or herbal remedies.
• You have any allergies, including allergy to mice or hamsters.
• You are breastfeeding. It is not known if ADVATE passes into your milk and if it can harm your baby.

What should I tell my HCP before using ADVATE? (continued)

• Are breastfeeding. It is not known if ADVATE passes into your milk. It is not known if ADVATE can harm your baby.

What important information do I need to know about ADVATE?

• You have an allergy to ADVATE. If you have an allergy to ADVATE, it may cause you to have a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, diziness, nausea or vomiting. Do not attempt to infuse yourself with ADVATE unless you have been taught by your HCP or hemophilia center.
• Your body may form inhibitor to factor VIII. An inhibitor is part of the body’s normal defense system. If you form inhibitors, it may stop ADVATE from working properly. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

What is the most serious side effect of ADVATE?

• Side effects that have been reported with ADVATE include cough, headache, joint swelling/aching, sore throat, liver injury, unusual taste, diarrhea, hemorrhage, abdominal pain, hot flashes, swelling of legs, dizziness, chills, sore face/ congestion, nausea/vomiting, sweating, and rash. Tell your HCP about any side effects that bother you or do not go away and if your bleeding does not stop after taking ADVATE.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088. Please see Important Facts about ADVATE on the following page and with your HCP.

For Full Prescribing Information, visit www.ADVATE.com.

Visit Learning Central at www.hfalearning.org to learn more about inhibitors and hear directly from the experience of community members.

While these courses are designed for people diagnosed with hemophilia A or B or VWD Type 3 who have infused with a clotting factor treatment product and their parents/caregivers, the courses are open to anyone who wants to learn more.

**ADVATE is for people in the United States who have hemophilia A (or B) or von Willebrand disease (VWD).**

**ADVATE is approved for people with hemophilia A.**

This work was supported by Cooperative Agreement Number, NU27DD001151-05, funded by the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.

1. In clinical trials, ADVATE demonstrated the ability to help prevent bleeding episodes using a prophylaxis regimen.

**ADVATE is approved for use in adults and children 12 years of age and older.**

1. [ADVATE Prescribing Information](https://wwwADVATE.com).

Reference: ADVATE Prescribing Information.

Copyright © 2023 Baxalta Incorporated, a Takeda company. US-ADV-0101v1.0 05/20

TAKEDA and the TAKEDA logo are trademarks or registered trademarks of Takeda Pharmaceutical Company Limited. Copyright © 2020 Takeda Pharmaceutical Company Limited. 300 Shire Way, Lexington, MA 02421. 1-800-828-2088. All rights reserved.

ADVATE Prescribing Information. www.hfalearning.org
How should I use ADVATE?

Be sure that your blood level of factor VIII is high enough to clot. You may have to have blood tests done after getting ADVATE to be sure your blood level of factor VIII is high enough.

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

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

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

What is ADVATE?

ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called “classic” hemophilia). The product does not contain plasma or albumin. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally. ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A. Your healthcare provider may give you ADVATE when you have surgery. ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis). ADVATE is not used to treat von Willebrand disease.

Who should not use ADVATE?

You should not use ADVATE if you:

• Are allergic to any ingredients in ADVATE.

Tell your healthcare provider if you:

• Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

• Are pregnant or planning to become pregnant. It is not known if ADVATE passes into your milk and if it can harm your baby.

• Are pregnant or planning to become pregnant. It is not known if ADVATE may harm your unborn baby.

• Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What should I tell my healthcare provider before I use ADVATE?

You should tell your healthcare provider if you:

• Have or have had any medical problems.

• Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.

• Have any allergies, including allergies to mice or hamsters.

• Are breastfeeding. It is not known if ADVATE passes into your milk and if it can harm your baby.

• Are pregnant or planning to become pregnant. It is not known if ADVATE may harm your unborn baby.

What are the possible side effects of ADVATE?

You can have an allergic reaction to ADVATE. Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, light-headedness, dizziness, nausea or fainting.

Side effects that have been reported with ADVATE include:

• Cough

• Headache

• Joint swelling/aching

• Fever

• Itching

• Diarrhea

• Chills

• Nausea/vomiting

• Sweating

Tell your healthcare provider about any side effects that bother you or do not go away.

These are not all the possible side effects with ADVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADVATE and Hemophilia A?

Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. It stops your body from coagulating. If you form inhibitors, it may stop ADVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

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

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADVATE. The FDA-approved product labeling can be found at www.advate.com or 1-877-825-3327.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

END THE CYCLE OF FINANCIAL STRUGGLE

New program provides a way for community members who often struggle financially to take steps to get ahead, stay ahead

BY ALLISON HARRISON, M.S.W., CERTIFIED FINANCIAL SOCIAL WORKER, STAFF WRITER

As a member of the Helping Hands team, I speak every day to members of the bleeding disorder community who are stuck in a cycle of financial insecurity. Hemophilia Federation of America’s Helping Hands team, staffed by social workers, connects with community members in need, delivers financial assistance and educates applicants about support that may strengthen their ability to succeed while living with a bleeding disorder.

While members of the bleeding disorders community are some of the most resilient and resourceful individuals, they also face a set of formidable challenges, such as high expenses due to medical appointments, procedures, medications, transportation to appointments, and items that are not covered by insurance like wheelchairs and protective gear. Many have faced ‘surprise billing’ issues when, in an emergency, they received care not covered by their insurance provider.

Employment

Some community members face challenges with income and financial stability. Because of physical needs or caregiving duties, people in the community may have a hard time finding work flexible enough to accommodate their physical needs. A bleeding disorder may also make it difficult for caregivers and patients to complete higher education that could open doors to higher wages.

We have seen many community members who are under-employed (hours or pay are too low to meet financial needs), find it hard to keep a job, find low-wage hourly work the only option, are overlooked for promotions or raises, or regularly miss out on wages due to caregiving or medical needs.

In HFA’s CHOICE Survey, a survey conducted by HFA several years ago to ask patients about their experiences, respondents with hemophilia A reported missing an average of 12 days of work or school because of their bleeding disorder. Respondents living with Hemophilia A with inhibitors missed an average of 23 days. The American Journal of Hematology published a study in 2015 stating nearly 25 percent of patients with bleeding disorders ages 25 to 34 were unemployed compared to 6 percent in the general population in the same year.

Family Impact

Bleeding disorders like hemophilia and vWD are usually hereditary, putting
community members at risk of facing the intergenerational impacts of both trauma and financial insecurity. Families with bleeding disorders have faced traumatic experiences, including long and painful bleeding episodes when treatments weren’t as effective, permanent complications, negative interactions with medical institutions, bankruptcy and debt caused by medical bills and insurance restrictions, the contamination of the blood supply, and stigma from neighbors, schools and employers.

While treatments have advanced and individuals with bleeding disorders are able to live long and productive lives, living with a chronic disorder still produces emotional, social, medical, and financial challenges.

Some Helping Hands applicants face a short-term emergency, like insufficient savings to cushion the blow of temporarily lost income or an unexpected expense. With financial assistance, they soon get back on their feet. Other applicants face a financial emergency but are also in a cycle of debt or poverty due to employment challenges, medical/insurance setbacks, debt and credit problems, or any number of issues outlined above.

Since its creation in 1997, Helping Hands has continuously evolved to meet the needs of our most vulnerable community members. The program started by providing bleeding disorder families with funds offering a brief respite from the daily grind of chronic illness. Over the years, Helping Hands has furnished thousands of families with assistance with urgent basic living expenses, medically necessary items, fitness support, medical travel and tutoring support. The program has also provided financial support to the bleeding disorders community affected by natural disasters such as hurricanes and floods through the Disaster Relief Fund help to those impacted by the pandemic. But there is more to do.

Plan to End the Cycle of Financial Struggle

Our community members are experiencing physical, financial and mental stress on a daily basis. Many find themselves maxing out physically and emotionally with little left to field daily phone calls from bill collectors, re-apply for public benefit programs, research financial assistance programs, search for a job or job training, or strategize for financial sustainability.

The Helping Hands team proposed to—in addition to lending a “helping hand” to community members in crisis—develop a program to address the root causes of financial insecurity applicants face year after year, leading to the creation of the Helping Forward program, a program to empower community members to move forward from crisis into a sustainable future through career planning and financial management.

The current focus of Helping Forward is education, including:

- The Employment Rights and Self-Advocacy courses on HFA’s Learning Central featuring videos, quotes and stories from 18 different community members.
- Lessons include an introduction to the topic of employment for people with bleeding disorders, the Americans with Disabilities Act (ADA), the Family and Medical Leave Act (FMLA) and tips for self-advocacy in the workplace.
- Visit the website to sign up for the Helping Forward Network so you can learn and grow with the program.

NEED HELP NOW OR MOVING FORWARD?

Helping Forward:
www.hemophiliafed.org/helpingforward
Helping Hands:
www.hemophiliafed.org/helpinghands
Patient Assistance Portal:
www.hemophiliafed.org/patientsassistanceportal
The 86 women who were enrolled reported blood disorder diagnoses or symptoms of a blood disorder (including women who are carriers of bleeding disorders):

- 83% indicated they had a diagnosis for a bleeding disorder
- 15% indicated they were not diagnosed with a bleeding disorder
- 2% either were unsure or preferred not to answer

The disease groups represented in this survey were hemophilia A (22%), von Willebrand’s disease (20%), carriers of hemophilia A (15%), platelet disorder (9%), hemophilia B (8%), carriers of hemophilia B (6%), factor V (5) deficiency (4%), factor V-VIII (5-8) deficiency (2%), and factor VII (7) deficiency (2%), while 12% of participants did not respond with a disease type.

The following highlights what program participants reported about female bleeding disorders and gaps in knowledge and awareness that are being addressed in upcoming HFA educational programming.

Knowledge and Awareness of Signs and Symptoms of Bleeding Disorders in Women

To learn more about participants’ current knowledge of signs and symptoms of bleeding disorders in women, we assessed if respondents were able to identify the signs and symptoms of bleeding disorders in women, specifically heavy periods, a family history of bleeding, frequent nosebleeds, and bleeding after giving birth or a miscarriage. And whether they knew that frequent headaches are not a symptom of a bleeding disorder.

- More than half of the women (62%) correctly identified all of the symptoms of bleeding disorders in women. However, there appeared to be a gap in knowledge among the women 18-29 years old as the majority, 60%, answered incorrectly.
- We looked at individual symptoms and found almost all women, 93%, recognized heavy periods as a symptom of bleeding disorders in women, and 85% of the women correctly answered that the definition of menorrhagia is menstrual bleeding that lasts more than seven days.

Knowledge and Awareness of Diagnostic Testing

We examined how familiar women were with the clinical laboratory tests that are common during the diagnosis process.

- 33% of women without a BD diagnosis and 62% of women with a BD diagnosis knew that the Factor B Clotting Test measures the amount of factor 8 protein in the blood. There was increased awareness about the purpose of the von Willebrand Factor Antigen Test, as 50% of the women without a BD diagnosis and 79% of women with a BD diagnosis answered this question correctly (including 94% of women diagnosed with VWD).

Patient-Provider Relationships

In order to better understand the level of care women with a reported diagnosis for a bleeding disorder receive, we asked questions about whether they talk about or received diagnostic testing during their most recent visit.

- When we asked about diagnostic testing, 42% of the women with symptoms of a BD or were carriers, but did not...
# Blood Sisterhood

A Summary of HFA’s Blood Sisterhood Survey Data

- **7%** of diagnosed women do not routinely see a healthcare provider.
- **62%** correctly identified all symptoms of bleeding disorders in women.
- **85%** knew the definition of menorrhagia (abnormally heavy bleeding at menstruation).
- **93%** knew heavy periods are a symptom of bleeding disorders in women.
- **23%** of diagnosed women do not have a prescribed treatment plan in place.
- **69%** feel “extremely” or “very” confident in being a BD self-advocate.
- **58%** “always” or “frequently” experience joint problems.
- **64%** feel their self-advocacy knowledge is “very high” or “above average.”
- **69%** feel “extremely” or “very” confident in being a BD self-advocate.
- **42%** have had surgery because of their bleeding disorder.

Average age at bleeding disorder diagnosis: **24**
Exploring the science behind gene therapy research

Gene therapy research has the potential to bring an entirely new option to people with specific genetic conditions. Many gene therapies are in clinical trials to evaluate the possible risks and benefits for a range of conditions, including hemophilia. HemDifferently is here with gene therapy education, providing accurate information on the basics and beyond.

Want to stay in-the-know and receive the latest information to your inbox, including invitations to events?
Scan the QR code now or visit HemDifferently.com to sign up for updates.

No gene therapies for hemophilia have been approved for use or determined to be safe or effective.

THE 5 STEPS OF INVESTIGATIONAL GENE TRANSFER

One method of gene therapy currently being explored in clinical trials is called gene transfer. This approach aims to introduce a working gene into the body to determine if it can produce a needed protein.

**STEP 1**
**CREATING A WORKING GENE**
A working, or functional, copy of a mutated gene is created in a laboratory.

**STEP 2**
**BUILDING A THERAPEUTIC VECTOR**
To protect and deliver the working gene, scientists place it inside an empty viral shell.

**STEP 3**
**DETERMINING ELIGIBILITY**
As part of gene therapy research, eligibility requirements may be considered, including age, gender, and organ health. In addition, some patients may have immunity to the therapeutic vector, which could be determined by a blood test and could make them ineligible for a trial.

**STEP 4**
**DELIVERING THE WORKING GENE**
A single, one-time infusion in an appropriate clinical setting delivers large numbers of therapeutic vectors into the body.
Once in the body, the working gene is designed to provide instructions for the body to make the protein it needs on its own.

**STEP 5**
**MONITORING SAFETY AND EFFICACY**
Clinical trial participants are regularly monitored to better understand the safety of the gene transfer and to evaluate its effect on the body, including whether it is creating the needed proteins.
report a diagnosis, indicated that they had talked about diagnostic testing with their provider at their last visit, and 17% of this group indicated that they received a diagnostic test at their last visit.

- Approximately 7% of the women who self-identified as having a diagnosed bleeding disorder said that they do not routinely see a healthcare provider, all of whom were under the age of 50. In addition, we saw differences by the geographic region where women lived, as about 20% of the women with a diagnosis from the Northeast or the West did not see a provider regularly, while all of diagnosed women from the South or the Midwest indicated regularly seeing a provider. In addition, 23% of the women with a diagnosed bleeding disorder do not have a prescribed treatment plan in place with their provider. Once again, women from the Northeast and West have less treatment plans in place (54% reported having a plan) than women from the South or Midwest (86% reported having a plan).

### Medical History of Bleeding Disorder

For women who reported having a bleeding disorder diagnosis, we also asked questions about the women’s age at diagnosis and medical interventions to better understand the impact their bleeding disorders have on their medical history.

- The average age at diagnosis was 24 years, with the youngest being 0 years and the oldest being 55 years of age at diagnosis.
- When asked about surgery, 42% of the women surveyed indicated having had surgery as a result of their bleeding disorders. The percentage of women having surgery generally increased with the age of the women.

### Joint Health

With bleeding disorders, joint damage due to bleeding episodes in joints is the most common complication. We asked a series of questions to all the women (both those diagnosed and those still undiagnosed with a BD) about their joint health.

- Overall, 58% of the women indicated that they “always” or “frequently” experienced problems with their joints, such as pain, stiffness, loss of motion, or weakness. Among the women who chose these categories, 96% were over 29 years old.
- More than 75% of women with hemophilia B, VWD, and women who are carriers for hemophilia A reported “always” or “frequently” having joint problems.
- We asked how often their joint problems, such as pain, stiffness, loss of motion, or weakness, limit their daily activities, such as going to work or school, doing recreational activities, or taking care of themselves.
- Approximately one in four said “frequently” and one in 10 said “always;” the largest proportions of women who answered were hemophilia A carriers (39%), women with hemophilia A (32%), women with hemophilia B (33%), women with platelet disorders (43%), and women with VWD (47%).

### Quality of Life

To better understand the quality of life these women experience, we asked all the women (with and without a diagnosis) to estimate how many days out of the last 30 days they felt their pain made it hard for them to do their usual activities.

- About half (52%) of the women said they experienced limiting pain like this for either 0 or one to five of the last 30 days. However, 22% of the women indicated having limiting pain for more than two weeks during the last 30 days.
- We also asked during the last 30 days, how many days they felt their physical health and they felt their mental health was not good.
- The average response was that physical health was not good for about eight of the last 30 days, with the average number of not-good-days increasing with age.
- On average, mental health was not good for about nine of the last 30 days, with hemophilia A carriers and women with hemophilia B reporting the highest average number of days when mental health was not good.
- The women estimated that poor mental or physical health prevented them from completing their usual activities for on average between six to seven days of the last 30 days, with the number of days again increasing with age.

- Interestingly, when asked about their health in general, most women felt that they were either “good” (47%) or “very good” (31%), although none of the women felt they were “excellent.” In addition, we asked how often they felt overwhelmed by bleeding disorder concerns, to which 51% responded “never” or “hardly ever,” and 34% responded “sometimes.”

Finally, we asked a series of questions about interpersonal relationships to gauge how much social support these women have. Overall, responses to these questions indicated that most of these women have the relationships and social support they need.

### Self-Advocacy and Sources of Bleeding Disorders Information

We asked questions to better understand how comfortable all of the women who participated in the survey were with advocating for themselves and where they received information about bleeding disorders.

- The women expressed, for the most part, that they were confident in being self-advocates for bleeding disorders, as 36% said they were “extremely confident.”

---

**Region in which Participants Reside**

The region of the United States where participants lived was represented fairly equally between regions with slightly more women living in the south, Region 3, and slightly less women living in the west coast, Region 4.

### Region**

<table>
<thead>
<tr>
<th>Region</th>
<th>Number of Participants (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Region 1 Northeast</td>
<td>21 (24.4%)</td>
</tr>
<tr>
<td>Region 2 Midwest</td>
<td>21 (24.4%)</td>
</tr>
<tr>
<td>Region 3 South</td>
<td>27 (31.4%)</td>
</tr>
<tr>
<td>Region 4 West</td>
<td>17 (19.8%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>86</td>
</tr>
</tbody>
</table>
GO AHEAD.

Discover your sense of go. Discover HEMLIBRA®.

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?
Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.

• Do not inject yourself or another person unless you have been taught how to do so by a healthcare provider.

• Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.

• Inactive ingredients:

• L-aspartic acid.

What are the ingredients in HEMLIBRA?
Active ingredient:
emicizumab-khw
Inactive ingredients:
L-arginine, L-histidine, polyoxamer 188, and L-aspartic acid.

© 2019 Genentech USA, Inc. All rights reserved. EMI/061818/0106a(2)
HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan. The Genentech logo is a registered trademark of Genentech, Inc. All other trademarks are the property of their respective owners.

©2018 Genentech, Inc. All rights reserved.
Revised: 10/2018

For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.

The Medication Guide has been prepared by the U.S. Food and Drug Administration Revised: 10/2018

HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan. The HEMLIBRA logo is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan. The Genentech logo is a registered trademark of Genentech, Inc. All other trademarks are the property of their respective owners.
and 33% said they were "very confident." When asked about the bleeding disorders they knew most about, 26% felt they were "very confident," while 36% felt they were "very confident." Women older than 29 tended to rank their knowledge higher than women 18-29 years of age.

The most popular sources of bleeding disorders information were state/local chapters and HFA. Among women who reported seeking information daily, 50% of the women used state/local chapters and 25% used HFA. Among women who reported seeking information weekly, 36% of women used HFA and 31% used state or local chapters. Among women who reported seeking information on a monthly basis, 37% used state/local chapters and 25% used HFA.

Many women also reported getting information from NHF, as 34% of women seeking information on an annual basis indicated using NHF, followed by 30% using HFA and 21% using state/local chapters.

We also asked about which HFA specific activities the women participated in to get information about women and bleeding disorders. The majority of women indicated they used HFA’s social media, with more than half (55%) saying they used it either “a great deal” or “a moderate amount.” HFA’s Newsletter, Dateline Federation, is also a commonly used source, as 57% of the women used that either “a great deal” or “a moderate amount.” About 40% of the women said they used HFA’s website “a great deal” or “a moderate amount.”

Conclusions

Our findings indicate that more education targeting younger women between the ages of 18 to 29 years old may be needed on knowledge topics such as signs and symptoms of bleeding disorders in women and the purposes of different diagnostic tests, as well as the need to routinely see a provider and have a prescribed treatment plan. We also asked whether the Blood Sisterhood Program provides social support to those who participate. Among women, 40% indicated the program did not feel this way (30%) or were unsure (30%).

We also asked whether the Blood Sisterhood Program provides social support to those who participate. Of the women who reported seeking information from HFA, 25% used state/local chapters and 25% used HFA. Among women who reported seeking information weekly, 36% of women used HFA and 31% used state or local chapters. Among women who reported seeking information on a monthly basis, 37% used state/local chapters and 25% used HFA.

The most popular sources of bleeding disorders information were state/local chapters and HFA. Among women who reported seeking information daily, 50% of the women used state/local chapters and 25% used HFA. Among women who reported seeking information weekly, 36% of women used HFA and 31% used state or local chapters. Among women who reported seeking information on a monthly basis, 37% used state/local chapters and 25% used HFA.

The majority of women indicated they used HFA’s social media, with more than half (55%) saying they used it either “a great deal” or “a moderate amount.” HFA’s Newsletter, Dateline Federation, is also a commonly used source, as 57% of the women used that either “a great deal” or “a moderate amount.” About 40% of the women said they used HFA’s website “a great deal” or “a moderate amount.”

Many women also reported getting information from NHF, as 34% of women seeking information on an annual basis indicated using NHF, followed by 30% using HFA and 21% using state/local chapters.

We also asked about which HFA specific activities the women participated in to get information about women and bleeding disorders. The majority of women indicated they used HFA’s social media, with more than half (55%) saying they used it either “a great deal” or “a moderate amount.” HFA’s Newsletter, Dateline Federation, is also a commonly used source, as 57% of the women used that either “a great deal” or “a moderate amount.” About 40% of the women said they used HFA’s website “a great deal” or “a moderate amount.”

Many women also reported getting information from NHF, as 34% of women seeking information on an annual basis indicated using NHF, followed by 30% using HFA and 21% using state/local chapters.

We also asked about which HFA specific activities the women participated in to get information about women and bleeding disorders. The majority of women indicated they used HFA’s social media, with more than half (55%) saying they used it either “a great deal” or “a moderate amount.” HFA’s Newsletter, Dateline Federation, is also a commonly used source, as 57% of the women used that either “a great deal” or “a moderate amount.” About 40% of the women said they used HFA’s website “a great deal” or “a moderate amount.”

Many women also reported getting information from NHF, as 34% of women seeking information on an annual basis indicated using NHF, followed by 30% using HFA and 21% using state/local chapters.

We also asked about which HFA specific activities the women participated in to get information about women and bleeding disorders. The majority of women indicated they used HFA’s social media, with more than half (55%) saying they used it either “a great deal” or “a moderate amount.” HFA’s Newsletter, Dateline Federation, is also a commonly used source, as 57% of the women used that either “a great deal” or “a moderate amount.” About 40% of the women said they used HFA’s website “a great deal” or “a moderate amount.”

Many women also reported getting information from NHF, as 34% of women seeking information on an annual basis indicated using NHF, followed by 30% using HFA and 21% using state/local chapters.

We also asked about which HFA specific activities the women participated in to get information about women and bleeding disorders. The majority of women indicated they used HFA’s social media, with more than half (55%) saying they used it either “a great deal” or “a moderate amount.” HFA’s Newsletter, Dateline Federation, is also a commonly used source, as 57% of the women used that either “a great deal” or “a moderate amount.” About 40% of the women said they used HFA’s website “a great deal” or “a moderate amount.”

Many women also reported getting information from NHF, as 34% of women seeking information on an annual basis indicated using NHF, followed by 30% using HFA and 21% using state/local chapters.

We also asked about which HFA specific activities the women participated in to get information about women and bleeding disorders. The majority of women indicated they used HFA’s social media, with more than half (55%) saying they used it either “a great deal” or “a moderate amount.” HFA’s Newsletter, Dateline Federation, is also a commonly used source, as 57% of the women used that either “a great deal” or “a moderate amount.” About 40% of the women said they used HFA’s website “a great deal” or “a moderate amount.”

Many women also reported getting information from NHF, as 34% of women seeking information on an annual basis indicated using NHF, followed by 30% using HFA and 21% using state/local chapters.

We also asked about which HFA specific activities the women participated in to get information about women and bleeding disorders. The majority of women indicated they used HFA’s social media, with more than half (55%) saying they used it either “a great deal” or “a moderate amount.” HFA’s Newsletter, Dateline Federation, is also a commonly used source, as 57% of the women used that either “a great deal” or “a moderate amount.” About 40% of the women said they used HFA’s website “a great deal” or “a moderate amount.”

Many women also reported getting information from NHF, as 34% of women seeking information on an annual basis indicated using NHF, followed by 30% using HFA and 21% using state/local chapters.
We all have our favorite things — the things we go to for comfort and familiarity. It might be that cozy sweater on a snow day or rainy Sunday afternoon. Or that mug that fits our hands just right and seems to make the coffee taste better.

It might be a special person. The one we go to when we've had a bad day and just need a shoulder to cry on. The one we share all our hopes and dreams with. That was the inspiration for a song written by bleeding disorders community member and singer-songwriter Trevor Martin of Nashville.

"I really wanted to impress a girl," said Martin, 23, who was diagnosed with severe hemophilia A as an infant. At 13, Martin had his eyes on a girl, and began writing songs using love stories as inspiration. For one of his most recent song releases, "Go-To," the message is about a girl who knows what she likes. At the end of the day, he/the singer hopes he will be one of her go-tos.

The road from writing songs for a girl at 13 to releasing songs that are now on YouTube and music streaming services started when Martin attended an event for Tennessee Hemophilia and Bleeding Disorders Foundation while in college. During the THBDF event, Martin's family met music producer Adam B. Smith, who has a son with hemophilia. Smith is a successful producer who has worked with internationally-known music artists such as Andy Grammer and Colbie Caillat. Smith and his wife, Tara, invited Martin for dinner where he had the chance to meet Arlo, the Smith's son with hemophilia. Martin says it was factor night and the Smiths had the chance to meet Arlo, the Smith's son with hemophilia. Martin and the Smiths developed a hemophilia connection that year, but life and school got in the way and a musical connection would come later. After graduation from Belmont University, Smith and Martin reconnected and began working together regularly, writing more than 20 songs together. In May he released "Go-To" with Smith's help. Music has been an outlet for Martin who, despite loving sports, couldn't participate in contact sports due to hemophilia.

"It’s a way to express myself without being too hard on joints," said Martin. "I want kids to know you can live a life of hemophilia that’s fun and exciting!"

In addition to recently released singles, Martin has written theme songs for movies and has done some acting. He placed second in the 2018 Music for a Cause hemophilia-based songwriting competition and won first place in the 2019 competition for his song "Way Back Home." He continues to be active in the hemophilia community and is grateful for his connection with Adam Smith.

"Not only has the music aspect been really cool, but the hemophilia aspect has been cool. It’s a great connection with Adam and Arlo," said Martin. "The hemophilia community has been great to me. There have been a lot of people who were inspirational to me and I hope to be an inspiration to someone too."

"GO-TO"
Available on Spotify, Apple Music, Amazon Music
Written in collaboration with hemophilia dad, Adam B. Smith.

"CALLING IT FRIENDS"
Available on Spotify, Apple Music, Amazon Music

More than 20 years* of experience—the first recombinant treatment for individuals with hemophilia B
Dosing options to meet your needs—for once-weekly prophylaxis and on-demand use
Designed with viral safety in mind. More than 150 quality control tests are done on each batch of BeneFix
The convenience of the BeneFix Rapid Reconstitution (R2) Kit with a range of vial sizes

What Is BeneFix?
BeneFix, Coagulation Factor IX (Recombinant), is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Your doctor might also give you BeneFix before surgical procedures. BeneFix is NOT used to treat hemophilia A.

Important Safety Information
- BeneFix is contraindicated in patients who have manifested life-threatening, immediate hypersensitivity reactions, including anaphylaxis, to the product or its components, including hamster protein.
- Call your health care provider right away if you are developing blood clots, such as a venous catheter through which BeneFix is given by continuous administration by continuous infusion. BeneFix may increase the risk of abnormal blood clots. The safety and efficacy of BeneFix administration by continuous infusion have not been established.
- Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness, and rash.

Please see the Brief Summary for BeneFix on the next page.
What is BeneF ix?

BeneF ix is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease.

Your doctor might also give you BeneF ix before surgical procedures.

BeneF ix is NOT used to treat hemophilia A.

What should I tell my doctor before using BeneF ix?

Tell your doctor and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal medicines.

Tell your doctor about all of your medical conditions, including:

• any allergies, including allergies to hamsters.
• if you are pregnant or planning to become pregnant. It is not known if BeneF ix enters your unborn baby.
• if you are breastfeeding. It is not known if BeneF ix passes into the milk and if it can harm your baby.

How should I infuse BeneF ix?
The initial administrations of BeneF ix should be administered under proper medical supervision, where proper medical care and efficacy of BeneF ix have not been established.

These are not all the possible side effects of BeneF ix. Tell your doctor about any side effect that bothers you or that does not go away.

How should I store BeneF ix?

DO NOT FREEZE the BeneF ix kit. The BeneF ix kit can be stored at room temperature (below 86°F) or under refrigeration. Throw away any unused BeneF ix and diluent after the expiration date indicated on the label. Freezing should be avoided to prevent damage to the pre-filled diluent syringe.

BeneF ix does not contain a preservative. After reconstituting BeneF ix, you should store it at room temperature for up to 3 hours. If you have not used it in 3 hours, throw it away.

Do not use BeneF ix if the reconstituted solution is not clear and colorless.

What else should I know about BeneF ix?

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

If you would like more information, talk with your doctor. You can ask your doctor or pharmacist for information about BeneF ix that was written for healthcare professionals.

This brief summary is based on BeneF ix (Coagulation Factor IX [Recombinant]) Prescribing Information LAB-0464-12.0, revised June 2020.

What are the possible side effects of BeneF ix?

Allergic reactions may occur with BeneF ix. Call your doctor or get emergency treatment right away if you have any of the following symptoms:

• wheezing
• fast heartbeat
• difficulty breathing
• chest tightness
• turning blue
• hives

Your body can also make antibodies, called “inhibitors,” against BeneF ix, which may stop BeneF ix from working properly.

Some common side effects of BeneF ix are:

• injection site reaction
• injection site pain
• headache
• dizziness
• blood clots

Blood clots are a more serious side effect of BeneF ix. They can form in your blood clots in critically ill neonates, while receiving continuous-infusion BeneF ix through a central venous catheter. The safety and efficacy of BeneF ix administration by continuous infusion have not been established.

If you have used BeneF ix and develop any of the following symptoms, call your doctor or a hospital immediately:

• if the reconstituted solution is not clear and colorless.

A rare but serious allergic reaction called anaphylaxis can occur with BeneF ix. If you develop this reaction, you should stop using BeneF ix and get emergency treatment right away.

If you have any of these reactions, do not use BeneF ix again.

If you pass out or feel dizzy, have difficulty breathing, or hives last more than 30 minutes, talk with your doctor.

If you have any other side effect:

• that bothers you
• that lasts
• that you think may affect your ability to do daily activities

Call your doctor or pharmacist before using BeneF ix. Your doctor will prescribe the dose that you should take.

Please read this Patient Information carefully before using BeneF ix and each time you get a refill. There may be new information. This brief summary does not take the place of talking with your doctor about your medical problems or your treatment.

Other Ways to Give

There are many ways you can make a contribution to Hemophilia Federation of America as the end of year approaches. Donations are tax-deductible and support our efforts to advocate for the bleeding disorders community.

It’s a great way to double your gift!

Annual Giving

Nov. 15 to Dec. 31

Donate online at www.hemophiliafed.org or send a check to 999 N Capitol St NE, Ste 201, Washington, D.C. 20002.

All donations will support Helping Hands, our financial assistance program.

Check if your employer will match your donation by using our simple search tool on hemophiliafed.org/matchinggifts.

It’s a great way to double your gift!

Annual Membership

Renew or initiate an individual, professional, or corporate membership today! Individual memberships start at just $35.00.

Visit www.hemophiliafed.org/membership.

We’re Stronger WITH Your Support!

With your help, HFA will be able to deliver educational programming, help families experiencing a financial crisis, advocate for the bleeding disorders community and so much more. Thank you in advance for your generosity and support.

PP-BEN-USA-0470 © 2020 Pfizer Inc. All rights reserved. July 2020
MoRe CoRe.
Our new CoRes.

The Sanofi Genzyme Community Relationship and Education (CoRe) team is growing. With our larger team, we’ll be able to bring a higher level of personalized attention to patients affected by rare blood disorders.

To us, it’s personal.

We’re here for you. Let’s connect.
Call us at 855-693-5628
Visit Facebook @HemophiliaCoRes

© 2020 Genzyme Corporation. All rights reserved.
HEM-US-6995 01/20