Joint Health: The Knowledge and Understanding of Maintaining Healthy Joints with a Bleeding Disorder
page 22

Weaving a Vibrant Tapestry: LGBTQ+ and the Bleeding Disorders Community
page 8

Access to Health Insurance During a Pandemic
page 18
Dear Friends,

I realize I might be new to some of you, so I wanted to share a little bit about myself as the new chair for the HFA Board of Directors. When I was young, I was diagnosed with von Willebrand Disease during an unexpected emergency surgery. After receiving my bleeding disorder diagnosis, as many of you can probably relate, it answered so many lingering questions I had, but it was a hard transition for my family. My mom had undiagnosed vWD and one of my sisters was diagnosed as well. Thankfully, I got connected with the Bleeding Disorder Foundation of Washington, which is my proud home and local member organization. I am so grateful for all the opportunities to learn, grow and lead with the incredible programming, and investment of the HFA’s programs and my local member organization. I’ve proudly served on the Bleeding Disorder Foundation of Washington’s Board for five years and have been on the board of directors for HFA for the past three years. I’m currently receiving my master’s in Health Administration at the University of Washington so I get to work toward strengthening our healthcare system and bringing better access for all. I’ve worked for Seattle Children’s Hospital in the Behavioral Health Department starting as a Pediatric Mental Health Specialist and now in leadership, guiding initiatives and getting to start new clinics. In my work I have the privilege of working with some of the kids that struggle with the most severe mental health disorders. Though there are some hard days, I see so much hope and resilience in them, just like I see in this community.

I also just got married a few months ago! And as a woman with a bleeding disorder, I’m now entering into conversations about how my bleeding disorder impacts my future family. HFA is so much more than an organization for people with bleeding disorders. It is, for me as a woman, future mom, and community member, a place of family and community strength that offers hope, assistance, educational tools and advocacy to everyone. Like so many of us, we need HFA to be the rock we can depend on for all of these things as we move together through the next decade and beyond, building on the lessons of the past. Through all of the history in our community, we proudly look to the future, strategizing how we can best move our blood brother, sisters, families and friends forward.

COVID – 19 has also brought in it’s own set of challenges. On top of managing our bleeding disorders we are now faced with hard decisions about our jobs, school, and seeing friends and loved ones. These decisions can exacerbate feelings of uncertainty and loneliness. I’ve found comfort in embracing the daily small joys of life, such as a walk outside, phone call with a friend, or a yummy meal. It’s more important than ever to take care of our mental and emotional health, whether that’s small acts of self-care or reaching out to a professional resource. HFA is here with you during these hard times.

As board chair I’m excited and ready to work with all of you to help strengthen HFA to continue the amazing work that’s been happening for the past 26 years. I, along with HFA board members, HFA staff and local member organizations, are with you.

Allie Ritcey
Board Chair

EXECUTIVE CORNER

HFA Welcomes Newest Board Chair

ARTICLES

Weaving a Vibrant Tapestry — Bleeding disorders community members who also find a place in the LBGTQIA+ community share their experience.

Seeking Health Insurance Coverage During COVID-19 — We explore the options for bleeding disorders patients and families to find healthcare.

Joint Health — A look at what we learned during a joint health survey with participants of HFA’s Blood Brotherhood and Families programs.

SPECIAL FEATURES

A Look at Symposium Symposium 2020 quickly turned into a successful virtual event and HFA plans ahead for Symposium 2021.

Find Your Place — A look at HFA’s program areas and how to connect to like-minded individuals and families in the bleeding disorders community.

ON THE COVER. Hemophilia Federation of America surveyed families and blood brothers on their knowledge of joint health and physical activity safe for joints. We break down the results of the survey and what we discovered. Read more on page 22.
Join us in San Antonio...

FOR HFA’S ANNUAL
SYMPOSIUM
OCTOBER 21-24, 2021

San Antonio, TX

Polish those boots and toss on your hat — it’s time to saddle up and head to Texas for #HFA2021! We’re bringing the largest patient-focused conference in the bleeding disorders community to the Lonestar state in the culturally-rich city of San Antonio.

We’re planning to be able to meet safely in person, but, especially after the success of our 2020 virtual Symposium, our team is exploring ways to ensure Symposium’s content and offerings can be accessed by everyone who wants it in-person and virtually. We’ve got some good things up our sleeves; stay tuned!

When Hemophilia Federation of America choose the theme for its 2020 Symposium — Charting Our Future — it was a play on the nautical history of Baltimore, the city where the annual educational event was to be held. The theme also emphasized HFA’s goal of improving the quality of life for the community now while always looking into the future. But as Symposium approached, the shift in sails that would need to take place to bring our community together quickly shifted from an in-person event to a unique virtual experience.

The online conference allowed community members to receive the educational content they’ve come to expect from Symposium, tapping into the expertise of speakers often found at the in-person version. Community members also had the opportunity to visit partners in the virtual Exhibit Hall and give a “virtual hug” to their friends with chat features.

FIRST VIRTUAL SYMPOSIUM BRINGS FAMILY TOGETHER AGAIN

When Hemophilia Federation of America choose the theme for its 2020 Symposium — Charting Our Future — it was a play on the nautical history of Baltimore, the city where the annual educational event was to be held. The theme also emphasized HFA’s goal of improving the quality of life for the community now while always looking into the future. But as Symposium approached, the shift in sails that would need to take place to bring our community together quickly shifted from an in-person event to a unique virtual experience.

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Thank You!

TO THE FOLLOWING SPONSORS FOR MAKING SYMPOSIUM 2020 A SUCCESS:

**DIAMOND**
- Biomarin
- Genentech
- Novo Nordisk
- Takeda

**PLATINUM**
- Bayer
- Sanofi Genzyme

**GOLD**
- CSL Behring
- Pfizer

**BRONZE**
- Grifols
- Hema Biologics
- Kedrion Biopharma
- UniQure

**VISITOR HIGHLIGHTS**

- 1,290 total unique attendees
- Maximum people attending at one time: 360
- 58,055 total content views
- 9,755 total webinar views
- 36,715 total booth entries
- 9,830 total auditorium entries
WEAVING A
VIBRANT TAPESTRY

Challenges and celebrations living an authentic life as an LGBTQIA+ person with a bleeding disorder

BY ANDY ANDERSON, GUEST WRITER

Like a vibrant tapestry, individual experiences unite to create something bigger than ourselves. Just as is the case in society at large, some voices within the bleeding disorders community may be marginalized. This past June, which the United States sets aside as Pride month, LGBTQIA+ members of the bleeding disorders community shared their experiences.

“There’s a sense that the bleeding disorders community is very diverse,” says Shellye Horowitz, licensed school counselor. From her home in California, Shellye talked about her experiences as a queer woman with hemophilia. “We have different religions, different politics, but we are united by a disorder that is serious enough that it helps us transcend our differences.”

Yet people with bleeding disorders who do not identify as heterosexual or cisgender may not feel entirely welcome at the table.

“The strength I developed as a child gave me the fortitude and power to come out and be proud of who I am,” says Thomas Savage of Iowa. “When I came out to my HTC because I thought it was important [information] for them to know how to support me. They didn’t really know what questions to ask but were great about it.”

— Guadalupe Mota

The strength I developed as a child gave me the fortitude and power to come out and be proud of who I am.

— Guadalupe Mota

Health, he wears many hats. Both identities are an important part of who he is, and it’s not so easy or necessary to separate one from the other.

“The strength I developed as a child gave me the fortitude and power to come out and be proud of who I am,” he said. Increased visibility of LGBTQIA+ people and a willingness to discuss experiences paves the way for a reality where a queer identity and a bleeding disorder are treated not as contradictions or overlapping challenges, but simply as two parts of a whole person. Going beyond the simple inclusion of

LGBTQIA+ identities in the bleeding disorders world deserves space and support to address the unique needs one experience may bring.

“Growing up with hemophilia helped me when I was coming out because it’s one of those things that we have that no one sees. If I didn’t tell someone I had a bleeding disorder, they didn’t know,” says Thomas Savage. “I came out to my HTC because I thought it was important [information] for them to know how to support me. They didn’t really know what questions to ask but were great about it.”

— Thomas Savage

Growing up with hemophilia helped me when I was coming out because it’s one of those things that we have that no one sees. If I didn’t tell someone I had a bleeding disorder, they didn’t know.

— Thomas Savage

The Trevor Project, an organization that supports LGBTQIA+ people in bleeding disorders, said in a 2018 interview both the LGBTQIA+ and the bleeding disorders communities were decimated by the HIV/AIDS epidemic. Despite significant improvements in detection and treatment, men who have sex with men are still routinely discriminated against in health policy and the public eye as potential transmitters of the virus. Some people want to distance themselves from HIV because they believe it is caused by irresponsible sex practices or illicit drug use, but with more than 10,000 hemophiliacs unknowingly infected through their medications, this community, more than others, should understand that moral or social failing is not the cause of HIV.

“I didn’t grow up with the hemophilia community. I grew up with the HIV+ community,” says Shellye. “My dad was infected when I was in middle school.

LATE SUMMER 2020
He had a lot of gay friends because that was his HIV+ peer group. She had her family spent the better part of her teens participating in public education efforts to help put a face to people living with HIV. She now uses the skills she developed then to advocate for women with hemophilia. She draws parallels between the experience of navigating a hemotypical world as a person with hemophilia and navigating a heterosexual world as a lesbian. “There’s a powerful transformation that happens when you’re able to understand and speak your truth.”

Discrimination in Resources and Treatment
While it is illegal to discriminate on the basis of sex, gender or orientation, LGBTQIA+ people are more likely to be discriminated against in public venues, including employment. I work in construction,” says Eleanor Anderson. “Every time I meet a new worker, I worry they might be rude to me because I’m a woman. Or worse, if they find out I’m transgender. I also worry about what would happen if I was injured on the job. Will I get to the hospital in time for them to stop the bleeding? What if I lose health insurance?”

First, it’s important to understand yourself and your needs before you can communicate those to others. “If you’re not ashamed of who you are,” says Rich, “it should be a part of the conversation.”

Couples seeking to grow their family may also face significant cost. “I want a big family someday,” laughs Eleanor. Family planning expenses may run as high as $100,000 and aren’t always covered by insurance. Couples also face the question of whether or not they want their child to have a bleeding disorder. The Hemophilia Foundation of Michigan offers an adoption program for parents who seek to specifically adopt children with hemophilia.

Rich Pezzillo, Executive Director of the New England Hemophilia Association, who looks forward to growing his family with his husband and is excited by the prospect of having a child with a bleeding disorder.

Common Thread
While those interviewed have different stories, they shared some common beliefs:

- First, it’s important to understand yourself and your needs before you can communicate those to others.
- “If you’re not ashamed of who you are,” says Rich, “it should be a part of the conversation.”

What do a bleeding disorder, sexual orientation and gender identity have in common? They’re important to who we are as a community. Show up as your full, authentic self in clinic, at bleeding disorders events and beyond.

If you’re not ashamed of who you are, it should be a part of the conversation.
— Rich Pezzillo

Let’s make today brilliant.
Takeda is here to support you throughout your journey and help you embrace who you are. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world, is stronger than ever.

bleedingdisorders.com

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WE’RE IN THIS TOGETHER.
No gene therapies for hemophilia have been approved for use or determined to be safe or effective.

Scan the QR code now or visit HemDifferently.com to sign up for updates.

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?

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.
HFA’s programs

Each member of the bleeding disorders community has unique needs and a desire to connect to those with similar experiences. What women with bleeding disorders experience can be far different than men and a one-size-fits-all approach to programming would not serve the community well. As a result, HFA has four distinct program areas — Blood Brotherhood, Blood Sisterhood, Families and Sangre Latina. Learn about each area, who it is intended to serve and what it means to join the program.

Families

— WHO IS IT FOR?
For parents and caregivers of a child with a bleeding disorder and children with bleeding disorders, through all stages of their journey.

— WHAT IT MEANS TO JOIN:
• Being the first to know about HFA’s events for parents and caregivers of children with bleeding disorders, joining a national community of other parents/caregivers managing a child with bleeding disorders, getting support and building a community to unite your peers at a local or regional level.
• Receive education that meets your unique needs as a parent or caregiver managing a bleeding disorder. HFA also offers age appropriate education for children and siblings. We do this by partnering with your local member organization, at national events, and through online education.

— WHY JOIN?
Social connection, education and personal advocacy skills, find out about urgent state and federal policy issues that you can weigh in on.

— HOW TO JOIN:
• Go to HFA’s website: www.hemophiliafed.org/families
• Give us a call: (202) 675-6984
• Email Carrie, Programs Director, at c.koenig@hemophiliafed.org

“The HFA Families Program has had a huge impact on my family. It’s given us feelings of support and empowerment. We also feel good about helping other families deal with emotions of having a child with a bleeding disorder.”

HFA encourages participation in these programs to stay connected and informed. HFA also partners with 50+ member organizations throughout the country. Local programs and events vary and the reasons to join listed on these pages are suggestions. Connect with your local organization to learn more about the services and events available in your area in addition to joining HFA Programs.

Sangre Latina

— ¿PARA QUIÉN?
Educando a las familias hispanas que tienen un desorden del sangrado.

— PARA QUE UNIRSE:
• HFA ofrece a la comunidad hispana educación en su idioma nativo, español.
• Brinda la oportunidad de unirse a la comunidad nacional y permanecer en contacto con ellos.
• Nuestros programas son pertinentes, de buena calidad y culturalmente apropiados.
• Sangre Latina brinda capacitación en su organización local de miembros de HFA, en el simposio anual de HFA, seminarios web educativos, TEACH Immersion en español y otros trastornos de sangrado o en línea.
• Tenemos un Chat mensual en español para estar conectados.

— ¿POR QUÉ UNIRSE?
Al unirse a Sangre Latina, usted tiene la oportunidad de saber primero de nuestros programas educativos nacionales para aumentar sus conocimientos sobre trastornos de sangrados. Nuestro objetivo es crear líderes en la comunidad y que estén bien preparados en autodefensa en beneficio de su familia y su comunidad local.

— ¿Cómo es un año de Sangre Latina?
Usted puede participar en nuestros programas asistiendo a sesiones en su organización local de miembros de HFA, en el simposio anual de HFA, seminarios web educativos, TEACH Immersion en español y otros trastornos de sangrado, en línea o participando de el chat virtual “Hablando Contigo” que comienza el 29 de julio y que se llevará a cabo todos los últimos miércoles de cada mes (Necesita registrarse. Vea la página web de Sangre Latina para más información).

— COMO UNIRSE:
• Inscribase a través del sitio web de HFA en www.hemophiliafed.org/sangre-latina/programacion/
• Nuestra Oficina. (202) 675-6984
• Contacte a Martha Boria, vía correo electrónico a m.boria@hemophiliafed.org o al (202) 868-2020

“Al unirme a Sangre Latina encontré una comunidad que entendió por lo que yo estaba pasando como Hemo-mamá.”
Blood Brotherhood

— WHO IS IT FOR?
This program serves to unite a diverse, nation-wide community of men with the common thread of living with a bleeding disorder.

— WHAT IT MEANS TO JOIN:
• Engage with more than 750 other adult men facing similar challenges and share techniques to manage your disorder.
• Be the first to hear about national events hosted by HFA and attend HFA events hosted by your local organization, with education and sessions catered specifically to you. (Blood Brotherhood programming varies by geographic location.)
• Network with other men in via regular video chats moderated, run, and populated solely by men with bleeding disorders.

Blood Brotherhood helped me get rid of a lot of stress and bond with my fellow hemophiliacs. It’s a great support group!"

— WHY JOIN?
Continue the time-honored tradition of Blood Brotherhood: connect and reconnect with friends that will last decades. Learn the latest developments in the ever-evolving world of bleeding disorders. The newest medicines, the best current techniques to manage pain, and how to advocate for your rights. Other reasons to join:
• Attend a legislative day at your local statehouse.
• Learn what issues call for your urgent advocacy.
  • Sit in a rap session after a delicious dinner with your fellow Blood Brothers.
  • Fly into a new city to take part in an HFA nationwide event, designed and catered to increase your knowledge and expand your metaphorical toolbelt.
• Attend Symposium, an annual event of more than a thousand people in our community.

— HOW TO JOIN:
• Enroll through HFA’s website: www.hemophiliafed.org/bloodbrotherhood
• Give us a call: (202) 675-6984
• Email Eric Burgeson, Blood Brotherhood Coordinator at e.burgeson@hemophiliafed.org

Blood Sisterhood

— WHO IS IT FOR?
For women with bleeding disorders, regardless of diagnosis, through all states of their journey.

— WHAT IT MEANS TO JOIN:
• Be the first to know about HFA’s events for women with bleeding disorders, joining a national community of your peers, getting support and building a community to unite your peers at a local or regional level. (Blood Sisterhood programming varies by geographic location.)
• Receive valuable education that meets your specific needs as a woman with a bleeding disorder. We do this by partnering with your local member organization, at national events, and through online education.

— WHY JOIN?
In addition to connecting with more than 600 other women with bleeding disorders, you’ll get first dibs on attending HFA’s national events. The education and soft skills training we provide can help you advocate for yourself in the doctor’s office, with government, and even at home.

— HOW TO JOIN:
• Enroll through HFA’s website: www.hemophiliafed.org/bloodsisterhood
• Give us a call: (202) 675-6984
• Email Carrie, Programs Director, at c.koenig@hemophiliafed.org

Other benefits of being a Blood Sister:
• Attend a weekend lunch and learn with your local bleeding disorders organization.
• Connect with Blood Sisters from across the country at HFA’s annual Symposium.
• Participate in research specifically geared toward women with bleeding disorders.
• Advocate at your statehouse and on Capitol Hill.
• Find the right tools to talk about your bleeding disorder with healthcare providers.

Q: DO I NEED TO HAVE A BLEEDING DISORDER DIAGNOSIS TO JOIN BLOOD SISTERHOOD?
A: No! If you suspect you have, are being evaluated for, or have a family member with a bleeding disorder, you are welcome to join.
Seeking HEALTH INSURANCE coverage DURING COVID-19

BY KIMBERLY RAMSEUR, JD, M.P.H., STAFF WRITER

This year has brought about many new things, especially changes to how you access health insurance. For the bleeding disorders community, having access to quality comprehensive coverage has always been a priority. Unfortunately, due to COVID-19, it has now become a priority for many other individuals who have found themselves looking for ways to gain access to or maintain health insurance.

While COVID-19 may have been unexpected, obtaining coverage outside traditional enrollment periods is not uncommon. Specific events may now qualify you for a Special Enrollment Period including, but not limited to:

- Changes in employment
- Changes in residence (Relocated)
- Changes in household
  - Marriage
  - Divorce
  - Death of a spouse
  - Birth
  - Adoption
- Changes in eligibility due to age
- Changes in school status (part-time vs. full-time)

If you are searching for coverage options, you may be eligible for COBRA, or a plan with potential subsidies via the Affordable Care Act Marketplace, or possibly your state Medicaid program. You may also qualify for other unemployment insurance benefits.

COBRA

The Consolidated Omnibus Budget Reconciliation Act (COBRA) allows employees who have lost jobs, experienced a reduction in work hours, job transition, a death in the family, divorce and other life events to continue health insurance benefits for a limited time. If you decide to take advantage of COBRA benefits, you may be required to pay the entire premium for coverage up to 102% of the plan’s cost. If you believe that COBRA is not your best option for accessing health insurance, you can enroll in a Marketplace plan instead.

ACA MARKETPLACE

The health insurance exchange, also called Marketplace, is where you go to purchase a health insurance plan for you and your family. Upon providing requested information, you can find a plan specific to your needs or see if you qualify for another form of assistance like Medicare or Medicaid. You can also find out if you are eligible for subsidies or lower costs on your monthly premiums and lower out-of-pocket expenses for private insurance plans and/or for free or low-cost coverage through Medicaid or the Children’s Health Insurance Program (CHIP). Most people who do not qualify for Medicaid may qualify for subsidized coverage. Subsidies are available in all 50 states and cover most, if not all, of your premium. To be eligible, you must expect to earn at least 100% of the Federal Poverty Level ($12,760 per year for an individual, or $26,200 per year for a family of four) for the entire 2020 calendar year. Subsidies are calculated based on how much money a household expects to earn for the whole calendar year. The lower a household’s projected income, the greater the likelihood of receiving a more substantial subsidy.

MEDICAID

In states that have expanded Medicaid, benefits are available to anyone with qualifying or no income; you can sign up at any time and pay very low premiums. Under traditional Medicaid programs, individuals who do not qualify because their income is too high, or who live in one of the 13 states that have chosen not to expand Medicaid, might still qualify for public health insurance based on current monthly income. This is especially true for children, pregnant women, and, to a lesser degree, parents.

UNEMPLOYMENT BENEFITS

Unemployment insurance is a joint state and federal program that provides cash benefits to eligible individuals who are fully unemployed or partially unemployed through no fault of their own. Eligible persons can file for unemployment benefits without a waiting period if they have experienced a change in employment status due to COVID-19. Please note, however, that while unemployment benefits are a joint effort between the state and federal government, states establish their own rules for eligibility and distribution of benefits, so be sure to research your specific state’s guidelines. Also, depending on your state, eligibility for unemployment benefits may only apply to full-time employees and not include some part-time, temporary, or self-employed workers.

HFA knows how important it is for people with bleeding disorders to maintain comprehensive health insurance coverage and urges you to do your research and protect yourself against imposter websites. Avoid anything that sounds misleading, questionable, or “too good to be true.” Make sure the plan you want covers the needs of you and your family. Try steering clear of short-term or skimpy plans. They often do not meet ACA consumer protection standards and will not provide adequate coverage for a person living with a bleeding disorder. Lastly, do not delay your search for coverage. While you may qualify for a special enrollment period, many programs offer a limited amount of time to sign up. If you miss this window of opportunity, absent another exception, e.g., you gain employment that provides health insurance benefits, you will have to wait until the traditional enrollment period and likely risk losing access to much-needed treatment and services.

To explore coverage options, visit Healthcare.gov or InsureKidsNow.gov.
Find helpful resources on HFA’s COVID-19 Informational Hub at www.hemophiliafed.org/covid19.
What is the most important information I should know about HEMLIBRA?

HEMIBLEIRA 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.

HEMIBLEIRA 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 injuries 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 HEMIBLEIRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - vomiting
  - 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 HEMIBLEIRA:
  - cough
  - shortness of breath
  - chest pain or tightness
  - feel faint
  - headache
  - change in vision

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 HEMIBLEIRA?" for more information about side effects.

What is HEMIBLEIRA?

HEMIBLEIRA 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 HEMIBLEIRA?

HEMIBLEIRA 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.

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

Before using HEMIBLEIRA, 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 HEMIBLEIRA may harm your unborn baby. Females who are able to become pregnant should use birth control.
- are breastfeeding or plan to breastfeed. It is not known if HEMIBLEIRA 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 professional when you get a new medicine.

How should I use HEMIBLEIRA?

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

- Use HEMIBLEIRA exactly as prescribed by your healthcare provider.
- Do not inject a new HEMIBLEIRA vial before it is needed.
- Use a single-use syringe checklist or checklist on the label to check for these:
  - right medicine
  - right dose
  - expiration date
- Stop (discontinue) prophylactic use of bypassing agents the day after a bleeding episode.
- You may continue prophylactic use of FVIII for the first week of HEMIBLEIRA prophylaxis if you are bleeding.
- HEMIBLEIRA is given as an injection under 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 HEMIBLEIRA 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 HEMIBLEIRA 1 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 HEMIBLEIRA 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.

HEMIBLEIRA 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 HEMIBLEIRA?

See “What is the most important information I should know about HEMIBLEIRA?” for a complete list of possible side effects.

The most common side effects of HEMIBLEIRA include:

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

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

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 HEMIBLEIRA?

- Store HEMIBLEIRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMIBLEIRA in the original carton to protect the vials from light.
- Do not shake HEMIBLEIRA.
- If needed, unopened vials of HEMIBLEIRA can be stored out of the refrigerator and then returned to the refrigerator. HEMIBLEIRA 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 HEMIBLEIRA is transferred from the vial to the syringe, HEMIBLEIRA should be used right away.
- Throw away any unused portion of HEMIBLEIRA.

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

General information about the safe and effective use of HEMIBLEIRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMIBLEIRA for a condition for which it was not prescribed. Do not give HEMIBLEIRA 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 HEMIBLEIRA that is written for health professionals.

What are the ingredients in HEMIBLEIRA?

Active ingredient: emicizumab-kowh

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

HEMIBLEIRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan.

For more information, go to www.HEMLIBRA.com or call 1-888-2HEMILBA. This Medication Guide has been reviewed by the Food and Drug Administration. Revised 11/2018.

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To better understand the knowledge and awareness of men and families with bleeding disorders of their physical activity and joint health, Hemophilia Federation of America surveyed participants enrolled in its Blood Brotherhood and Families programs. A total of 120 men (diagnosed with hemophilia A, hemophilia B or Von Willebrand Disease (VWD)) in the Blood Brotherhood program and 119 caregivers of children younger than 25 years old and diagnosed with hemophilia A, B or VWD in the Families program completed the survey.

HFA used this knowledge to tailor its educational programming activities to better fit participants’ experience and participation. The following highlights what program participants reported about joint health and gaps in their knowledge and awareness that are being addressed in HFA programming.

**Knowledge and Awareness of Safe Physical Activity**

To learn more about participants’ current knowledge of safe physical activity, we examined if they knew what was considered safe physical activities for a person with a bleeding disorder. Safe physical activity was defined as:

- Walking, running, jogging or hiking
- Yoga, martial arts, tai chi
- Swimming/aquatics
- Bicycling/spinning
- Cardio-aerobics, Zumba, Pilates, dance, motion fitness video games
- Weight training
- Cross-country/skiing
- Tennis
- Sports: baseball, basketball, tennis

Incorrect responses included selecting wrestling, football, BMX racing, downhill skiing, snowboarding, skateboarding or trampoline, which are not safe physical activities for supporting joint health.

**Knowledge and Awareness of Benefits of Regular Physical Activity**

HFA also examined if respondents knew the benefits of participation in regular physical activity. Correct benefits of regular physical activity was defined as building healthy joints, having a gentle impact on bones, muscles and joints, or building self-esteem and self-confidence. Incorrect benefits of regular physical activity was defined in the survey as decreasing good cholesterol (HDL), increasing weight, and increasing the risk of developing spontaneous joint bleeds. Most participants from both programs correctly identified one or more safe physical activities and could also identify one or more benefits in engaging in regular physical activity.
### Blood Brotherhood

- **80%** men physically active at the time of the survey
- **76%** want to be more physically active

### Families

- **84%** children engaged in physical activity during the 6 months prior to the survey
- **87%** children physically active at the time of the survey
- **73%** number of parents/caregivers planning to help children become physically active
- **18 to 33%** concerned about children being overweight
- **85%** children engaged in regular physical activity
- **60%** men engaged in regular physical activity in six months prior to the survey
- **54%** men indicated they wanted to lose weight
- **70%** men engaged in physical activity on a regular basis

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Understanding of Weight Intention and Physical Activity

HFA also asked participants about their intention to lose weight and their or their child(ren)’s physical activity practices with the following questions:

- Intention to lose weight: Which of the following are you trying to do about your weight? with the choice of lose weight, gain weight, stay the same, not trying to do anything about your weight, and don’t know. (This question was only measured for men.)
- Current physical activity: I (my child(ren)) is/are currently physically active, with the choice of yes or no.
- Intention for physical activity: I (my child(ren)) intend to become more physically active in the next six months, with a choice of yes or no.
- Regular physical activity: I (my child(ren)) currently engage in regular physical activity, with a choice of yes or no.

Blood Brotherhood

- Over half (54%) of the men indicated they wanted to lose weight.
- The majority of men, 80%, reported being physically active at the time of the survey.
- Most men (76%) reported a desire to become more physically active in the near future.
- About 70% of men were currently engaged in physical activity on a regular basis.
- 60% reported engaging in regular physical activity in the past six months.

Families

- Most parents/caregivers indicated that they had no weight concerns for their children, but 18 to 33 percent reported overweight concerns for their children (child 1 and child 2 respectively).
- The majority of parents/caregivers (87%) reported that their children were physically active at the time of the survey.
- 73% of parents/caregivers intended for their children to become physically active in the next 6 months.
- 85% reported their children were currently engaged in physical activity on a regular basis.
- 84% reported that their child(ren) had been regularly engaging in physical activity in the past six months.

Understanding of Joint Problems and Feeling Overwhelmed

- Half of the men reported frequent joint pain while the other half reported never or rarely experiencing pain. Most of the men who had joint pain were 50 to 59 years old. Of the 41 men who responded to this question, 52% indicated they always or frequently had joint problems, while 48% indicated that joint problems rarely or never limited their daily activities.
- The majority of men reported never or hardly ever being overwhelmed by their bleeding disorder. When respondents were asked about feelings of being overwhelmed by their bleeding disorders, 60% of men reported that they were never or hardly ever overwhelmed.
- Of the caregivers who correctly identified safe physical activities, 40 to 62% of their children reported never or rarely have joint problem. Eighty-nine percent (89%) and 73% of parents/caregivers indicated that joint problems do not limit daily activities for their child whether they correctly and incorrectly identify one or more safe physical activities, respectively.

Source of Joint Health Information

We wanted to know what ways survey participants received information about health, wellness and physical activity.

Blood Brotherhood participants said they receive this education through:
- HFA’s annual Symposium educational conference
- Dateline magazine, HFA’s quarterly print magazine

Parents and caregiver participants said they receive this education through Dateline, social media and Symposium.

Discover more about IXINITY®

Visit IXINITY.com
Conclusions
Our findings regarding joint health and safe physical activity knowledge are consistent across both Families and Blood Brotherhood program participants. Men appeared to be fairly educated on what were considered safe physical activities and the benefits of engaging in regular physical activities. However, one in five men still could not accurately identify safe physical activity and the benefits of physical activity. Education on different types and levels of safe physical activity and the benefits of said physical activity would be beneficial as the definition of what was considered as safe physical activity was broad.

With regards to identifying safe physical activities and benefits to engaging in regular physical activities, parents/caregivers appeared to be knowledgeable, but how safe physical activities were defined could be further explored. However, HFA discovered one in four caregivers still could not accurately identify safe physical activity and the benefits of physical activity.

For the men, among all of HFA activities, Symposium, HFA’s annual educational conference and HFA’s quarterly magazine appear to be most effective. The quarterly magazine, social media and Symposium are resources that parents and caregivers ranked the highest of HFA’s resources for education on physical activities education, while webinars did not appear to resonate.

HFA recognizes the need to further improve awareness and knowledge of joint health among patients, families and caregivers.

To address the need for further education, HFA developed comprehensive learning courses in the Health and Wellness Center of HFA’s Learning Center, an online learning platform at www.hfalearning.org. The courses offer participants the opportunity to learn the basics of joint health, physical activities that are safe for joints, exercise videos and modifications to exercise, based on their level of physical activity. It is intended to provide education for people with bleeding disorders, their families, healthcare professionals, and anyone who wants to learn more about joint health.

HFA would like to thank the Blood Brotherhood and Families program participants who took their valuable time to complete the 2017 baseline survey. The information collected from this survey provided HFA with a better understanding of the knowledge about joint health and where the organization could engage the community to increase knowledge and awareness. This information is not meant to be reflective of the knowledge of all program participants, however, the gaps identified provide HFA with a better understanding about what education is needed and how HFA can best deliver this education to meet the needs of our program participants. HFA will continue to use this data to develop interventions aimed at increasing knowledge and awareness about the safe physical activity and joint health.

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

FOR ADULTS AND ADOLESCENTS

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

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.
• PK trough level goal is 0% for prophylaxis.
• Data shown are from a study where 17% previously treated adolescents and adults received routine prophylaxis with Esperoct® 50 IU/kg every 4 days.
• 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.

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 or get emergency treatment 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
• Call your healthcare provider right away or get emergency treatment 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

Move beyond the threshold®

Esperoct® can give you high factor levels for longer.*
What to tell my healthcare provider before I start taking ESPEROCT®

You should tell your healthcare provider if you:

• Have or have had any medical conditions.
• Take medicines, including prescription medicines and dietary supplements.
• Are pregnant or nursing.
• Have been told that you have antibodies to Factor VIII.

How should I use ESPEROCT®?

Treatment with ESPEROCT® should be started by a healthcare provider who is experienced in the care of patients with hemophilia A. ESPEROCT® is given as an infusion into the vein.

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

What is ESPEROCT®?

ESPEROCT® 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 in all age groups that prevents blood from clotting normally. ESPEROCT® is used 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.

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®
• Are allergic to hamster proteins

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

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

What should I tell my healthcare provider before I start using ESPEROCT®?

You should tell your healthcare provider if you:

• Have or have had any medical conditions.
• Take medicines, including prescription medicines and dietary supplements.
• Are pregnant or nursing.
• Have been told that you have antibodies to Factor VIII.

How should I use ESPEROCT®?

Treatment with ESPEROCT® should be started by a healthcare provider who is experienced in the care of patients with hemophilia A. ESPEROCT® is given as an infusion into the vein.

You may infuse ESPEROCT® at a hemophilia treatment center, at your healthcare provider’s office or in your home. You should be trained in 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 ESPEROCT® to use based on your weight, the severity of your hemophilia A, and where you are bleeding. Your dose will be calculated in international units, IU.

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

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 ESPEROCT® or even a different product to control bleeding. Do not increase the total dose of ESPEROCT® to control your bleeding without consulting your healthcare provider.

Use in children

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

If you forget to use ESPEROCT®:

If you forget a dose, infuse the missed dose when you discover the mistake. Do not infuse a double dose to make up for a forgotten dose. Proceed with the next infusions as scheduled and continue as advised by your healthcare provider.

If you stop using ESPEROCT®:

Do not stop using ESPEROCT® without consulting your healthcare provider.

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

What I take too much ESPEROCT®?

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

What are the possible side effects of ESPEROCT®?

Common Side Effects Include:

• rash or itching
• swelling, pain, rash or redness at the location of infusion

Other Possible Side Effects:

You may have an allergic reaction to coagulation Factor VIII products. Call your healthcare provider right away or get emergency treatment right away if you get any signs of an allergic reaction, such as:

• hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.

Your body can also make antibodies called “inhibitors” against ESPEROCT®, which may stop ESPEROCT® from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time. These are not all of the possible side effects from ESPEROCT®. 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 ESPEROCT® dosage strengths?

ESPEROCT® comes in five 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 five different strengths are as follows:

- 1000 IU per vial
- 1500 IU per vial
- 2000 IU per vial
- 3000 IU per vial
- 4000 IU per vial

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

How should I store ESPEROCT®?

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

• Do not freeze ESPEROCT®. ESPEROCT® can be stored in refrigeration at 36°F to 46°F (2°C to 8°C) for up to 30 months until the expiration date stated on the label. During the 30 month shelf life, ESPEROCT® may be kept at room temperature (not to exceed 80°F/27°C) for up to 12 months, or if 10°F (4°C) for no longer than 3 months.

If you choose to store ESPEROCT® at room temperature:

• Record the date when the product was removed from the refrigerator.
• 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:

The reconstituted (the final product once the powder is mixed with the diluent) ESPEROCT® should appear clear and colorless without visible particles.

The reconstituted ESPEROCT® should be used immediately.

If you cannot use the reconstituted ESPEROCT® immediately, it must be used within 4 hours when stored at or below 86°F (30°C) or within 24 hours when stored in a refrigerator at 36°F to 46°F (2°C to 8°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 ESPEROCT® and hemophilia A?

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

Revised: 10/2019

ESPEROCT® is a trademark of Novo Nordisk Health Care AG.

For Patient Information, refer to: http://novonordisk-us.com/patients/products/product-patients.html

More detailed information is available upon request. Available by prescription only.

Manufactured by:
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Novo Ali
DK-2880 Bagsvaerd, Denmark

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Plainsboro, NJ 08536, USA
1-800-727-6500

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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.

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