Coronavirus leads to cancellation of chapter events

Spring is usually a busy time for HACA: Chapter Education Day, support group gatherings, educational dinners, and more. But with the COVID-19 pandemic in full swing, the usual activities have been cancelled or postponed through May.

We have decided not to reschedule our annual Chapter Education Day in 2020. Between events we already have scheduled for the fall, like our Fall Festival and Walk, the rescheduled HFA Symposium, and the lack of weekends available for our sponsors to participate, we are hosting a series of webinars instead.

The first session on Monday, April 13, is on “Taking Care of You” and will be led by mental health counselor Debbie De La Riva. Learn some tips on coping with stress and anxiety during these unprecedented times. Click here to register.

Donnie Akers Jr., an attorney with expertise in elder, estate and small business law, leads the session “Legal Toolkit for Families” on May 6 at 7 p.m. The session will discuss legal matters for people with bleeding disorders, including special needs trusts and the ABLE Act. Click here to register.

Dr. Michael Guerrera of Children’s National Health System will lead a session on gene therapy on June 4; look for more details in future weekly updates. We also plan to have a financial planning/financial recovery session with Carolyn Walder of Lifetime Wealth Planning & Management in May.

We are also planning small group gatherings via Zoom. We recently had a women’s group check-in, and it was nice to see each other’s faces again!

You may also receive information about branded webinars from some of our industry partners. Many had already paid the chapter to participate in education day, and since it is cancelled, we are working with each one to come up with alternative opportunities.

Patient Assistance

We realize that many families will be affected financially because of job losses or furloughs. HACA has a patient assistance program for emergencies, and we will be designating extra funding to help members who are struggling during this time. Please reach out first to your HTC’s social worker or nurse, who will then direct you to the chapter for an application. If you have any questions, please email director@hacacares.org.

Factor Supply

The National Hemophilia Foundation is keeping tabs on manufacturers to provide updates. So far, there seems be no issue with the supply chain, but please click on this link to the NHF website for up-to-date information.

HTC Update

Dr. Michael Guerrera, hematologist at the Children’s National Health System HTC, said the center is trying to avoid patient visits until after April 17. He is offering telemedicine appointments until the clinic can be reopened. Please reach out by phone, email or through the portal for nonurgent needs. The center will continue to support all medication needs during the crisis.

The material provided in HACA News is for your general information only. HACA does not give medical advice or engage in the practice of medicine. HACA under no circumstances recommends particular treatment for specific individuals, and in all cases recommends that you consult your physician or treatment center before pursuing any course of treatment.

Publisher
Hemophilia Association of the Capital Area
Editor
Brenda Bordelon, Executive Director

Mission Statement
HACA’s mission is to support advocacy, education, and awareness efforts that build and sustain community among all people impacted by bleeding disorders.

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CHAPTER NEWS

Camp registration open through April 30

HACA and the Virginia Hemophilia Foundation (VHF) are teaming up again for Camp Youngblood in 2020! The dates are Sunday, July 5th – Friday, July 10th. Deadline to register has been extended to April 30, and no decisions have been made yet about camp in light of the coronavirus pandemic.

NEW THIS YEAR: In order to make the registration process run more smoothly, the enrolling parent or guardian will fill out a short Camp Youngblood prescreening survey to determine eligibility. This is required for all applicants, even returning campers.

Camp staff will review each survey and those who meet the criteria will be sent a password to access the 2020 Camp Youngblood application. Those who do not meet the criteria will be notified as well.

ALSO NEW IN 2020: We will also be offering a Family Camp weekend at Camp Holiday Trails (CHT) that will take place Friday, July 10th – Sunday, July 12th, which is immediately after the summer camp session. Families will participate in the same fun activities as campers, stay in cabins and come to know the meaning of "camp magic" at CHT. If you are interested in registering for Family Camp, add all your family members to your account before starting the application, then select “Camp Youngblood & Youngblood Family Camp Weekend” as your session. This is open to summer camp families only at this time.

The Camp Youngblood application process is open enrollment and not first come first served. This will allow VHF, HACA, and CHT the chance to review applications and manage the roster according to the application/admission guidelines. All application deadlines must be adhered to in order to be considered. Family Camp has limited space. Eligible families will be chosen from confirmed Camp Youngblood campers using a lottery system.

The application process is now open on the Camp Holiday Trails website. The deadline for submitting applications is April 30.

Save the date for summer, fall activities

With Maryland, DC and Virginia now all under Stay at Home orders until early summer, now is time to start planning your late summer and fall activities! Here are some events to look forward to, with more details to come!

In July, we are still planning on summer and family camp (see more details above), as well as our annual vWD Education Day on July 25. This year’s guest speaker is Dr. Danielle Nance.

Moving into August, we have a full slate of activities planned, bracketed by two national meetings. NHF is still planning its annual Bleeding Disorders Conference August 6-8 (see page 3 for details on applying for the Qualsey Scholarship to attend), and HFA has rescheduled Symposium for August 24-26. The chapter will have its annual picnic on August 16; the teen retreat will take place August 21-23, and the women’s retreat is back a little earlier this year, August 28-30.

The HACA Fall Festival and Walk is also a little earlier in 2020: Saturday, September 19, at Lake Accotink Park again. Look for a new and improved walk website to come in July. We will all need a reason to get together and celebrate, and our chapter walk is one of the highlights of the year.

October will feature the rescheduled Men’s Group outing at Top Golf (date still TBD), as well as the Families of Young Children Group.

November 14-15 will feature our rescheduled Richmond Days advocacy training with the Virginia Hemophilia Foundation, with a new format and activities to be revealed in the coming months. Our annual Spanish-language Education Day is on November 7, and the Men’s Retreat with VHF will also take place that weekend (November 7-8).

December will feature a special holiday women’s group activity, as well as the annual holiday gathering.

Also look for a variety of Dine & Discuss dinner events, as well as branded dinners for our Fall Festival & Walk top sponsors.

We are all doing our part to stay home and stay healthy now, but we hope to resume our activities in the summer and fall. Keep an eye out for more details in future Weekly Updates and newsletters.

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2020 HACA CALENDAR OF EVENTS

To register for any event, contact admin@hacacares.org or 703-352-7641.

APRIL
19 HACA Board Meeting via Zoom, 5-7 p.m.

Events are cancelled due to Stay at Home orders

MAY

Events are cancelled due to Stay at Home orders

JUNE
8 HACA Board Meeting
13 Families of Young Children Group
14 HACA Industry Symposium & “Bombardier Blood” Screening, AFI
Silver Theater, Silver Spring, MD

PAGE 2
Scholarship applications now available on website

HACA offers two types of scholarships each year: one is for education, the other for a trip to the NHF Annual Bleeding Disorders Conference, which is still scheduled for August 6-8 2020.

The annual George and Linda Price Scholarship application program is now up and running. There are two scholarships available, at $3,000 each, for the 2020-21 school year ($1,500 per semester). We have extended the deadline for returning the application to June 1, and this year the application, essays and referral letters can be sent via email. If there are any issues obtaining transcripts or recommendation letters due to the pandemic closures, please reach out to Brenda at director@hacacares.org so we can talk about other possible arrangements, or receiving at a later date. Click here for the application and guidelines.

The Sandi Qualley Scholarship for national meetings is offering a scholarship to attend the National Hemophilia Foundation’s Bleeding Disorders Conference, which takes place August 6-8 in Atlanta, GA (it is still scheduled to take place at this time). The deadline to apply is May 1. Click here for the application and guidelines.

COVID-19 delays national meetings

Due to the spread of the coronavirus, both the Coalition for Hemophilia B and the Hemophilia Federation of America rescheduled their respective Symposia that were planned for spring 2020.

The Coalition originally planned to hold its event March 19-22 but have rescheduled for June 6-9 at the Renaissance Orlando at Sea World in Florida. Participants were already chosen for the event, but a few spots have opened; if you are interested, reach out to the Coalition at kimp@hemob.org.

The Hemophilia Federation of America has changed its late April event until August 24-26 at the Hilton Baltimore Inner Harbor. Registration is still open; click here to find out more information. Scholarships have already been awarded, but if you are interested in attending and have financial difficulties, please reach out to Brenda Bordelon at HACA in case any of the scholarship recipients are unable to attend.

2020 board election coming up in May via SurveyMonkey

The Governance Committee of the Hemophilia Association of the Capital Area is working to select a slate of officers and new candidates to join the Board of Directors for 2020-21.

The chapter will distribute an anonymous survey at the end of April, and members will have a week to approve the slate. This is usually done during the annual meeting, which takes place at the Chapter Education Day, but because the March 28 event was cancelled, a vote will be taken online.

Please look for more information on the candidates to be distributed in late April.
Advocates gather in DC for annual Washington Days events

By Patti Williford

HACA members joined with other bleeding disorders advocates from around the country February 26-28 in Washington, DC for NHF’s annual Washington Days.

The event started on the evening of Wednesday, February 26 with a dinner and training at the Hyatt Regency on Capitol Hill. More than 450 attendees from 45 states gathered to learn about how to meet with their legislators, tell their story, and advocate for the needs of the bleeding disorders community. The evening ended with an entertaining and informative skit of what to do versus what not to do during your visit to Capitol Hill.

The next day started with breakfast and a quick legislative briefing. Then it was off to Capitol Hill for a full day of advocating. This year, NHF and HFA identified two areas of need within the community for us to focus on during our meetings with legislators and staff.

The first was asking for continued support of federal bleeding disorder programs through organizations such as the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH), and the Health Resources and Services Administration (HRSA). These programs provide funding for Hemophilia Treatment Centers and bleeding disorders research.

The second ask was that legislators co-sponsor the bipartisan bills for the Hemophilia Skilled Nursing Facilities Access Act. This legislation would allow Skilled Nursing Facilities (SNFs) to bill Medicare separately for clotting factor. Currently, SNFs cannot do this, which results in people with bleeding disorders being denied access to these facilities following incidents that require further care after leaving the hospital.

After a busy day of advocating, the event ended with dinner where the National Hemophilia Foundation’s new CEO spoke and introduced himself to the community. Some members then stayed on Friday to participate in additional training for state and local advocacy.

Teens meet for an afternoon of education and fun

By Patti Williford

The teens of the Hemophilia Association of the Capital Area came together on Saturday, February 22, at Dave and Busters in Springfield, Virginia for an educational program on advocacy.

Eight teens participated in the program “Your Voice Has Weight: Let’s Advocate!” led by Sarah Shinkman of the Hemophilia Federation of America. Attendees learned about the various places and ways they can advocate for themselves such as in school, at work, and regarding having a bleeding disorder. National and State advocacy events were also discussed, including what to know and how to prepare for these experiences. The program ended by learning about the importance of an elevator pitch and time for everyone to create and practice their own.

After the advocacy program, the teens enjoyed playing arcade games and time to socialize, as well as a buffet lunch. Thank you to everyone who attended! Keep an eye out for our next Teen Task Force meeting to take place this summer.
NHF board adopts four new MASAC documents

The National Hemophilia Foundation’s (NHF’s) Medical and Scientific Advisory Council (MASAC) issued four new documents, which were adopted by NHF’s Board of Directors on February 28, 2020.

MASAC Document #258, which replaces Document #255, represents the most up-to-date information relevant to emicizumab, including a brief description of the therapy and its indications. The document is dedicated to comprehensive guidance to help inform treatment decisions relevant to the use of emicizumab. It includes varied clinical scenarios, and the considerations that providers of hemophilia care should make when weighing the use of emicizumab, such as inhibitor status and management, breakthrough bleeds, surgery, laboratory assays, use of additional therapies. The document also includes a set of standard patient education guidelines, with concrete points of clinician-patient information sharing.

View and download Recommendation on the Use and Management of Emicizumab-kwxh (Hemlibra®) for Hemophilia A with and without Inhibitors.

MASAC Document #259 is the latest version of the council’s enduring and most broad-based treatment document, which includes descriptions of, and recommendations for, the use of all therapies currently approved by the U.S. Food and Drug Administration (FDA) to treat bleeding disorders. This document is accompanied by a list of these therapies, organized by bleeding disorder type. NOTE – The list includes hyperlinks to the FDA webpage dedicated to each approved product.

View and download MASAC Recommendations Concerning Products Licensed for the Treatment of Hemophilia and Other Bleeding Disorders.

View Products Licensed in the U.S.

MASAC Document #260 was designed as a special supplement to the guidelines issued by the U.S. Centers for Disease Control and Prevention (CDC) in 2016 for prescribing opioids for chronic pain. Created by the Pain Initiative Task Force of MASAC, the document provides guidance for multi-disciplinary healthcare providers who intend to integrate these guidelines into the care of their bleeding disorder patients. The authors highlight special considerations for these patients and share practical advice for effectively managing their chronic pain.

View and download Management of Chronic Pain in Persons with Bleeding Disorders: Guidance for Practical Application of The Centers for Disease Control’s Opioid Prescribing Guidelines.

MASAC Document #261 provides needed guidance on the use of prophylactic therapy in bleeding disorder patients who undergo gastrointestinal (GI) endoscopies, a procedure being employed more frequently to screen for underlying issues such as colorectal cancer. The document includes the baseline risk for GI bleeding by low and high-risk procedures as classified by American Society of Gastrointestinal Endoscopy. The subsequent recommendations lay out the requisite therapeutic target levels to minimize bleeding risk, along with specific guidance on prophylactic dosing for various bleeding and platelet function disorders, considering factors such as disease severity and inhibitor status.

View and download MASAC Recommendations for Bleeding Prophylaxis in Bleeding Disorder Patients Undergoing GI Endoscopy.

View the complete list of current MASAC documents.

MASAC supplemental statement

Patients on home therapy receive regular shipments of clotting factor concentrate (CFC) or non-factor replacement therapy (e.g., emicizumab-kwxh) from their pharmacy providers, often on a monthly basis or as home supplies are depleted. Having an adequate supply of these treatment products at home is critical to achieve safe patient care and continuity of treatment.

Moreover, a national emergency or natural disasters (e.g., hurricanes, tornadoes, floods, earthquakes) may occur, resulting in patients being cut off from delivery for several days. During these periods of time, the need to continue regular care regimens, including prophylactic treatment remains important. Lack of an adequate supply of treatment products to cover such situations might place patients at-risk for severe complications, including death.

Therefore, MASAC makes the following recommendations:

During a period in which a national emergency has been declared under the National Emergencies Act, or at such other times (e.g., declaration of a natural disaster, pandemic or other public health crisis) that it may reasonably be anticipated that there could be an interruption in supply, distribution, transportation or home delivery of clotting factor concentrates or non-factor replacement therapy (e.g., Emicizumab-kwxh) patients with bleeding disorder treated on regular prophylaxis should be able to obtain a prescription refill for their prophylaxis regimen when their home quantity reaches at a minimum an estimated two week’s supply.

When refills are provided under these recommendations, the doses remaining at home should not be deducted from the doses to be dispensed for the next delivery.

These recommendations are supplemental to those continued in MASAC Document #242 - MASAC Recommendations Regarding Doses of Clotting Factor Concentrate In The Home. The recommendations of MASAC Document 242 should apply during other periods of time.

Whether under these supplemental recommendations or the recommendations of MASAC Document 242, health plans, home care delivery companies, pharmacy benefit managers and pharmacies should allow exceptions to allow for early refill requests based on documented work, school or travel needs where home delivery on a timely basis would not otherwise be practical.
Historic legislative session comes to a close in Virginia

By Becky Bowers-Lanier
B2L Consulting

At the time of this writing, the 2020 General Assembly has adjourned, after voting on the budget bill on Thursday, March 12th. The Assembly is due to return on April 22nd to deal with any bills on which the Governor recommends changes. That said, we expect that the Governor will recommend changes in the biennial budget based on the fast-moving health, economic, and social upheaval caused by COVID-19. At the time of this writing, it’s too early to determine what changes to the budget that the Governor will suggest.

The legislative session was one of firsts:

- First time in a generation that the Democrats gained a majority in both the Senate and the House;
- First female Speaker of the House (Del. Eileen Filler-Corn);
- First time the bleeding disorder community canceled its annual advocacy day traditionally held on Martin Luther King Jr., Day.

While we missed our day, we thank you for advocating for bills when we’ve sent out calls to action, and we are still working to advocate for changes in insurance bills through our membership in the Healthy Market Coalition.

Del. Chris Hurst and Sen. George Barker HB 795 (Del. Hurst) and SB 235 (Sen. Barker) gained passage of two identical “association” health plan bills. Unfortunately, the plans may pull away people from the community risk pool that keeps a large number of people in the marketplace and helps to keep the cost of insurance lower for all.

A third insurance bill, SB 861, patroned by Sen. Monty Mason, is more problematic for our community. This bill would create a “benefits” consortium for eligible members. Because of its framing as a “benefits” plan, it does not need to abide by the provisions of the Affordable Care Act and therefore would be devastating for members of the bleeding disorders community. The plans could deny people with preexisting conditions and deny coverage for drugs. The Healthy Market Coalition is asking to Governor to veto this bill.

Two identical plans introduced by Del. Sam Rasoul and Sen. Ghazala Hashmi (HB 1037 (Del. Rasoul) and SB 404 (Hashmi)) will create short-term, limited duration health insurance plans for no more than 180 days in a year. These plans also do not have to adhere to all the requirements of the Affordable Care Act and may include no coverage for prescription drugs and pre-existing conditions, which are critical for our community. The plans carry higher premiums and cap services. Our community members should avoid carrying these plans, but they may work for younger, healthy people without preexisting conditions who need to get short-term insurance coverage.

Two bills, HB 1251 (Del. Torian) and SB 172 (Sen. Favola), deal with the problem of “surprise” billing which occurs when an individual seeks care in a hospital that is “in network” for the individual but out-of-network for providers in the hospitals who subsequently charge the individual with a large, unexpected bill. This sometimes happens in emergency rooms where the hospital is listed as an in-network facility, but the emergency room physicians are out of network. The patient gets left holding the bag for a large medical bill. HB 1251 and SB 172 are designed to take the individual out of the equation and leave the billing disagreement up to the provider/facility and the insurance companies.

Finally, we are hopeful that Virginia will create its own state-based insurance marketplace so that we can move away from the federally facilitated marketplace which we have had since the implementation of the Affordable Care Act. Moving to a Virginia marketplace should drive down the cost of health insurance. The exchange is not due to begin until the end of next year, but both bills providing for the implementation have passed the General Assembly and are on their way to the Governor for his signature.

All these measures sound wonky, and one can certainly get lost in the details. Before changing your insurance coverage, be sure to read the entire disclosures associated with each. Do they cover preexisting conditions? Do they cover the essential health benefits required of the Affordable Care Act? Do they have sufficient drug coverage with no annual caps? Can you receive subsidies for coverage costs? Be careful!

And finally, keep your social distances, wash your hands frequently, and if you run a fever, stay home. And watch the ever-changing news on the pandemic.
Catjammers come through with virtual jam session, fundraiser

A group of local bluegrass musicians known as the Catjammers recorded a virtual jam session on March 26 to raise money for HACA during Bleeding Disorders Awareness Month.

Many of the musicians are part of a local band called King Street Bluegrass, but they jam together monthly as the Catjammers to raise money for a local charity (they got the name from their first charity venture, raising money for a cat rescue organization).

The Catjammers started fundraising for HACA back in 2016, and have put on a show each March since then. This year’s jam raised $260, as of March 30.

Thanks to organizer Nancy Lisi, who sets up the event each year, and to Steve Long, former HACA president who brought the two groups together.

It’s not too late to see the show: Click here to view.

Thanks to our donors, sponsors

The Hemophilia Association of the Capital Area gratefully acknowledges our donors who have given so generously. Below are donations received from January 1-February 29, 2020. We have made every effort to ensure all donations are listed.

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Aptevo (now Medexus)
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Takeda is here to support you throughout your journey and help you embrace life’s possibilities. 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. Let's make today brilliant.

bleedingdisorders.com
News You Can Use: COVID-19 links and other information

COVID-19

Hemophilia Federation of America has a dedicated hub for coronavirus updates and information

The National Hemophilia Foundation is keeping tabs on product availability

The World Federation of Hemophilia has also issued statements on COVID-19

Keep up with the Centers for Disease Control and Prevention for guidelines and information

State health departments also update their information daily:

Virginia

Maryland

District of Columbia

If you are interested in seeing how states are responding through their state legislatures, click here

INDUSTRY NEWS

Industry forms alliance to develop potential treatment for patients with serious COVID-19 complications

Concluzumab trials halted

FDA approves new recombinant Factor VIIa therapy

Opioid prescriptions underreported for treating pain in hemophilia, study finds

uniQure achieves target patient dosing in HOPE-B pivotal trial of AMT-061
What is HEMLIBRA?
HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

What is the most important information I should know about HEMLIBRA?
HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider’s instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. HEMLIBRA may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

Please see Brief Summary of Medication Guide on following page for Important Safety Information, including Serious Side Effects.
Medication Guide
HEMLIBRA® (hem-lee-bruh) (emicizumab-kxwh)
injection, for subcutaneous use

What is the most important information I should know about HEMLIBRA?
HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider’s instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:

- Thrombotic microangiopathy (TMA). This is a condition involving blood clots and injury to small blood vessels that can cause brain, kidney, lung, and other organ damage. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - confusion
  - weakness or back pain
  - swelling of arms or legs
  - nausea or vomiting
  - feeling sick
  - decreased urination

- Blood clots (thrombotic events). Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - pain or redness in your arms or legs
  - numbness in your face
  - eye pain or swelling
  - fast heart rate

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

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

What is HEMLIBRA?
HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors. Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

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

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

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

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

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

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

- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first 4 weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. Do not give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

What are the possible side effects of HEMLIBRA?
See “What is the most important information I should know about HEMLIBRA?”

The most common side effects of HEMLIBRA include:
- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

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

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

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

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

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