FALL 2020

Infusions

Andrea Orozco, Executive Director

STAFF SPOTLIGHT

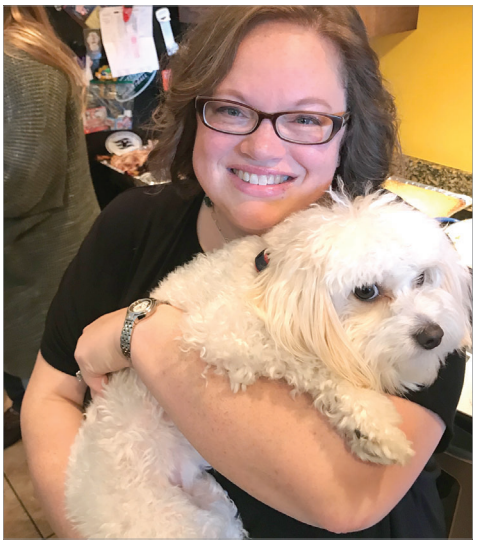
Andrea is new to the bleeding disorder community and has already begun to dig in! She brings over 15 years of experience working for large non-profit health organizations. Most recently, she served as a Senior Director for The Leukemia & Lymphoma Society. She also has done extensive development work for the American Heart Association, as well as the American Cancer Society. Prior to entering into the nonprofit world, Andrea worked in sales and marketing management for some major corporations: AT&T, Experian and Bank of America among them. Andrea wants you to know that she was "thrilled to accept this position and will strive to make HFNC a wonderful and caring home for our community". She looks forward to meeting each and every one of you when COVID-19 allows us to be together once more. Andrea is married to her husband, Mark and is the proud "bonus mom" to 3 wonderful young men, Joe, Jared and Brian. She's fun-loving "Grandma 'Drea" to 5 grandchildren. She and Mark enjoy spending their time traveling to America's National Parks in the lower 48 and to Alaska. Please join the Board of Directors and staff at HFNC in welcoming her.

IN THIS ISSUE

HFNC STANDS AGAINST DISCRIMINATION OF ANY FORM. WE ACKNOWLEDGE OUR RESPONSIBILITY TO BE A PART OF THE SOLUTION. THIS WILL INVOLVE EVERYONE COMING TOGETHER TO MAKE POSITIVE CHANGES. WE ARE COMMITTED TO DOING OUR PART.

VOLUNTEER SPOTLIGHT

Tyla Fowlkes



Hi! My name is Tyla Fowlkes. I am the Infirmary Coordinator for Camp Hemotion. This year would have been my 4th year volunteering there. I am from Tennessee, about 2 hours north of Memphis. I am also the Infirmary Director at Tennessee's Camp Freedom and have been there for 12 years. How did I start coming to a camp in California you might ask?? Most of you probably know Bobby Wiseman, who also came to Camp Freedom as a counselor for many years. When Camp Hemotion had a need for an Infirmary Coordinator, he called me up and asked if I'd like to come out his way! Since camps are a huge passion of mine, I couldn't pass it up and I am so thankful that I said yes! Everyone at Camp Hemotion and HFNC has welcomed me with open arms as part of the family! I have met so many people that I now consider close friends and family that I will have forever. I cannot say enough about how wonderful your community and the people in it are!!!

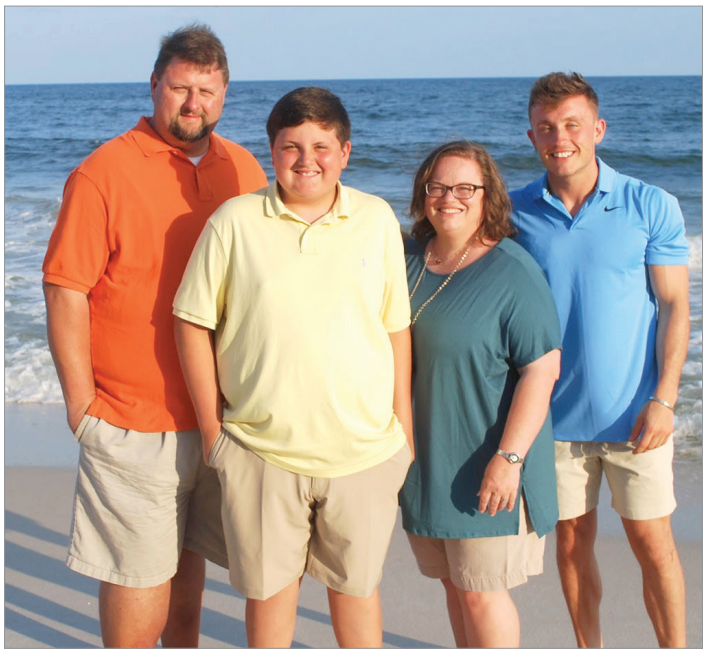
I have been a nurse for 21 years and have worked with patients with bleeding disorders for the past 13 years. I also have personal reasons for volunteering in the bleeding disorders community. My dad had severe hemophilia A, I am a carrier with lower factor levels, and I have 2 sons with severe hemophilia. When I started working with people with bleeding disorders, I knew I could give back from both personal and professional experience. Then, when a good friend asked me to help as a nurse at Camp Freedom one year, I was hooked! Since then I have volunteered every year at camp, as well as working as a nurse with GutMonkey on backcountry trips and GenIX programs for adults with bleeding disorders. I absolutely LOVE giving back to the community in this way and it is just good for the soul to me! Helping children, and adults, gain skills and confidence in various ways to take care of their bleeding disorder and be an advocate in the community is such a powerful thing. I am honored that I get to be a small part of that.

A little bit about me....

I live in the hot, humid South. I have a wonderful husband, Dan, my two boys, Zach and Will, and my fur baby, Baxter. Zach is 23, just graduated from the University of Memphis and is headed to graduate school at the University of Miami this August. Will is 14 and will be a freshman in high school this year. We could not be prouder of the men they are becoming and how well they take care of their hemophilia. We are active members of our Tennessee Hemophilia & Bleeding Disorders Foundation. Obviously, camp is one of my passions, and our whole family is passionate about advocacy. I am also a hobby cookier! I spend a lot of late nights and weekends cookie decorating! As a family, we are big college football fans and a baseball family! Until Covid-19 hit, I have been at a baseball field every Spring and Summer watching both of my boys play since Zach was little. I'm not sure what I will do when the day comes that I'm no longer a baseball mom. I guess I'll be making more cookies!

So, that's me!

I want to shout out a HUGE THANK YOU to everyone that I have worked with over the past few years! I feel so honored to be a part of the Camp Hemotion family and am so grateful for my experiences there! Looking forward to next year already!! Until then, I hope everyone stays safe and healthy!



Medication Guide
HEMLIBRA® (hem-lee-bruh)
(emicizumab-kxwh)
injection, for subcutaneous use

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

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

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen) or back pain
  - nausea or vomiting
  - feeling sick
  - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

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

See "**What are the possible side effects of HEMLIBRA?**" for more information about side effects.

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

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

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

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

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

How should I use HEMLIBRA?

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

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

What are the possible side effects of HEMLIBRA?

- See "**What is the most important information I should know about HEMLIBRA?**"

The most common side effects of HEMLIBRA include:

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

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

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store HEMLIBRA?

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

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

General information about the safe and effective use of HEMLIBRA.

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

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

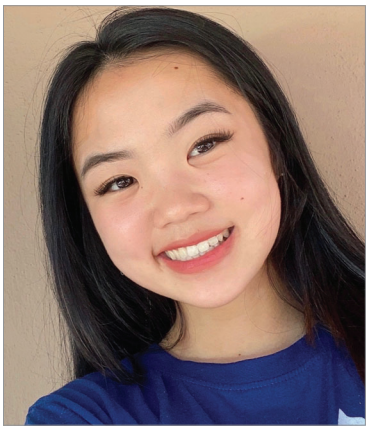
Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048

For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised: 10/2018

Genentech
A Member of the Roche Group

Junior Board Member: Kelly Yu



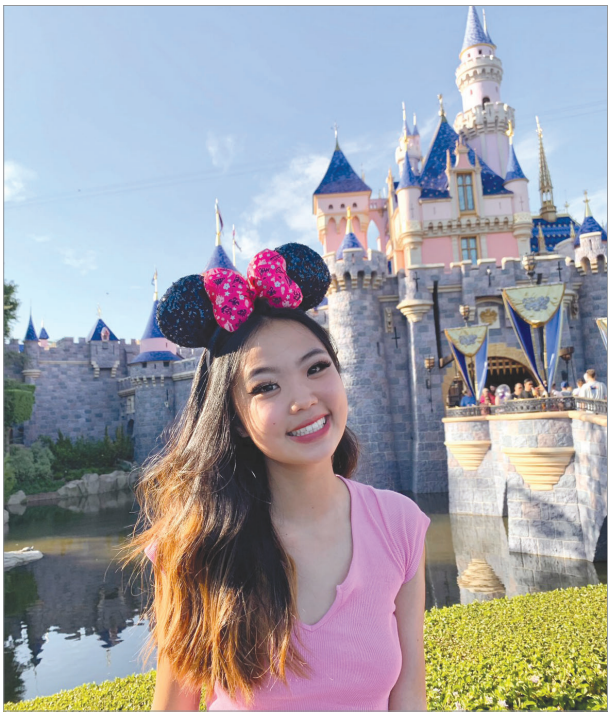
Hello all! :) My name is Kelly Yu and I am currently a junior at Castro Valley High School. I am very grateful to have the opportunity to be one of the junior board members for HFNC! I have Von Willebrands. During the early years when my menstruation first started, I noticed that I had unusual heavy bleeding. I asked my friends and family and they are all surprised that I had to use way more than usual products to control my bleeding. It can get so heavy to the point I would have to go to the restroom every hour and still leak through, it was very embarrassing, especially when it happened at school. My pediatrician at the time recommended me to get blood work done. After sixteen tubes of blood that were taken for blood tests, I got diagnosed with Von Willebrand disease. Over the years I switched pediatricians since I was moving from cities to cities and my Von Willebrand got kind of swept under the rug. My most recent pediatrician dug back the record because I updated her on the heavy bleeding and also the pain from my ovarian cysts. I also noticed how easy I bruised and how it takes longer than usual to recover. I got recommended to the UCSF Benioff Children's Hospital. There I met Kim Ross, she recommended for me to join HFNC, an amazing, wholesome community full of strong and unique individuals that I am so happy to be apart of today! I've learned a whole variety of other blood disorders/ diseases that I've never would've known about, and I can feel that I am not alone, Thanks to all of you :)

Daily Life/ Hobbies

As for my daily life and hobbies, I like to listen to a variety of music such as Korean Pop, R&B, or even just chill jazz beats to study. I enjoy watching "kdramas" and variety shows too. Before quarantine, I would play badminton on the weekends to train for my school badminton team, volunteer for my community service club, or to hang out with friends and study at a library. Now that all my usual activities have been hindered by COVID- 19, I am taking online medical courses and programs to stay educated and productive. I am very interested in pursuing a medical career in the future.

Interests/ Hopes for the future

I was born in China and I immigrated here when I was 6. As a child, I was in and out of a hospital quite a lot, suffering from high fevers and other illnesses. Till this day, I still am in and out of the hospital often, due to my Von Willebrand and also translating for my parents for their check- ups. The frequent interactions with medical staffs, HFNC, the hospital setting, and also witnessing issues such as addiction in my family drives my passion to pursue a medical career in the future. Specifically, a pediatric nurse. The medical community have given me so much, and I am eager to give back.



VOLUNTEER SPOTLIGHT

Mosi Williams

Hello Hemo Family!

My name is Mosi Williams, I have Severe Hemophilia A, and I am currently one of the Coordinators of the Junior Counselor/ Assistant Counselor Training Program at Camp Hemotion. I have attended Camp Hemotion as a camper and staff member for over 30 years! So, what keeps me coming back to camp year after year?

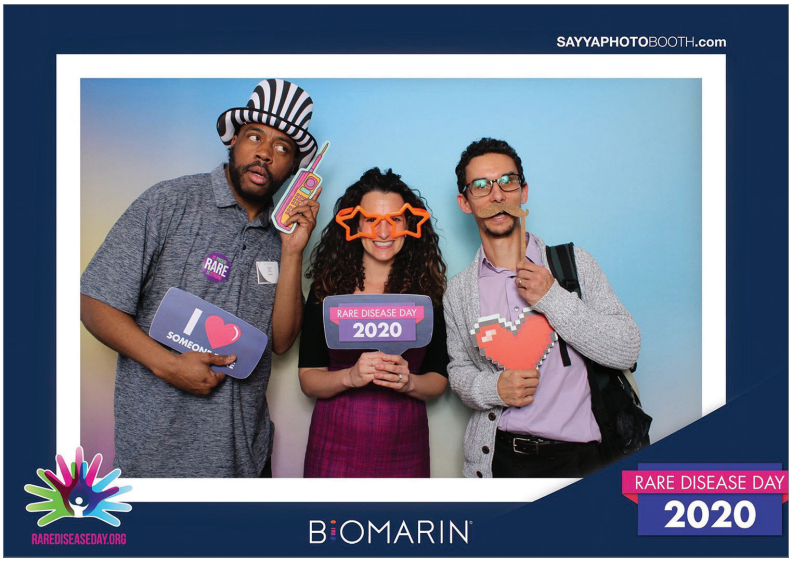
I started attending camp when I was five years old, and was a camper until I was fourteen. For me, camp was my safe space. It was the one place in my life where I didn't have to explain my Hemophilia to anyone and everyone. Growing up with Hemophilia - day after day I would have bleeds and not want to go to school because I had to answer 1000 questions about what happened, why I was perfectly fine yesterday, and students wanting to play with my crutches all day long. There was also bullying, teasing and name calling that went along with that. But, at camp, if I woke up with a bleed - sure, there was the infirmary to treat us - but there weren't these unending questions about what was wrong with me. I felt accepted at camp. Other campers had the similar physical struggles, so the focus was not on what we couldn't do, but what we could achieve together and how we could have fun doing it. Some of the activities that we currently offer at Hemotion- ropes courses, the rock wall, archery, zip-lines and of course Gaga– were things I never had the opportunity to do outside of camp because people were afraid that I would injure myself. So, I clung to the opportunity to return to camp each year, try new adventures, see old friends and make new ones. A lot of us old campers are still in touch to this day.

As a staff member now, my primary goal is to provide the same safe space of challenge and acceptance for our campers. Our staff often talks about the "camp magic" - those special moments that campers and staff can have that impact their lives and build confidence and courage that they can take into the outside world. Campers have conquered their fears of heights, and have learned independence through infusing themselves for the first time. Former campers have become camp counselors themselves, and in their careers have gone into education, Hemophilia advocacy, research, the sciences, and have become medical doctors, working in Hematology- giving back to our community. For myself, camp provided me my first experiences working as a counselor. I went to college to study counseling, and I currently work as a school counselor for students with health issues.

So, it all came full circle for me! That's my story, and I'm sticking to it. See you at camp next year!

The Hemophilia Foundation of Northern California
FOR ALL BLEEDING DISORDERS

Me and my Father



Fun at HFNC's Family Ed Day 2019

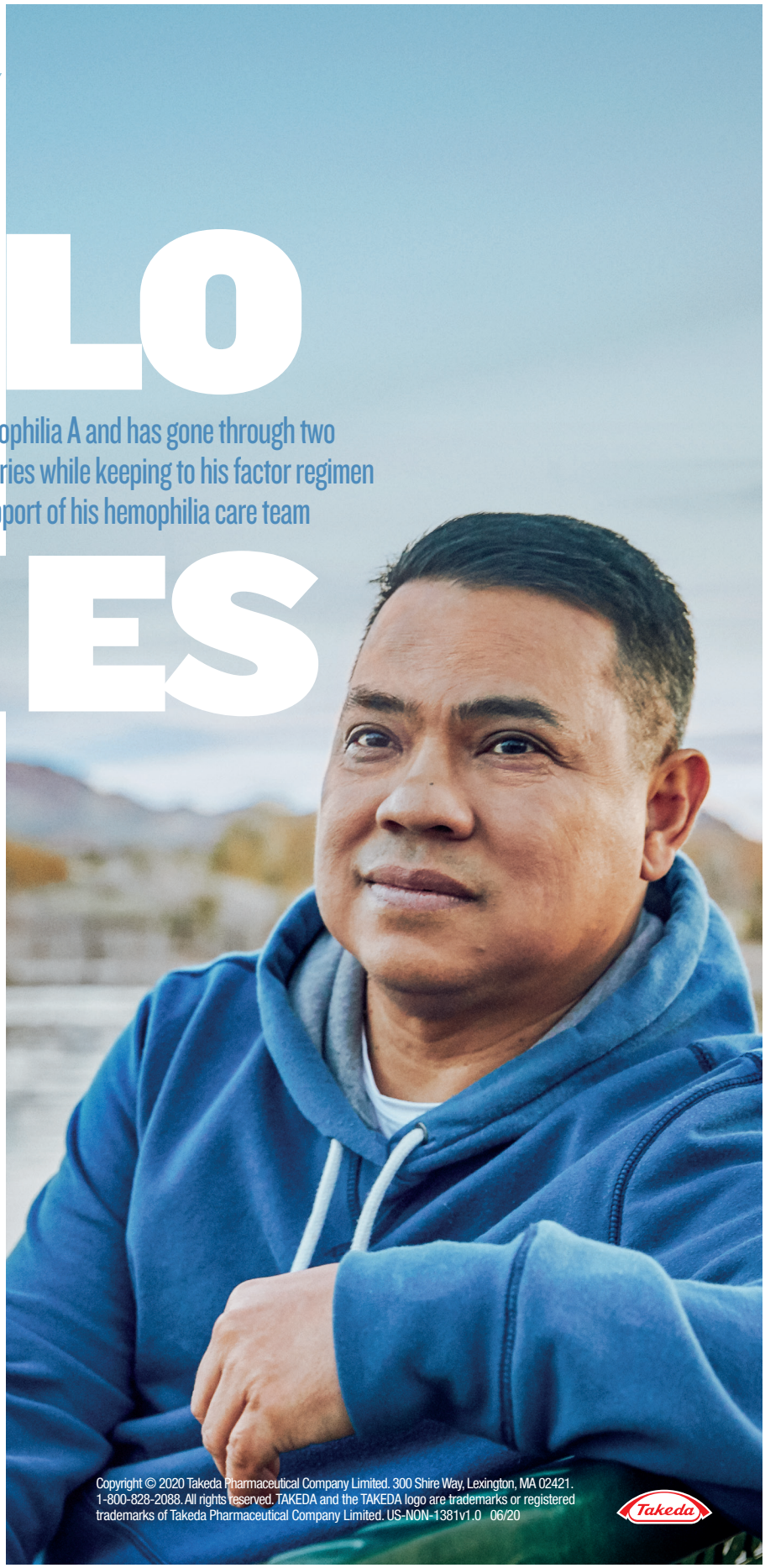
SAY HELLO TO JAMES

He has hemophilia A and has gone through two major surgeries while keeping to his factor regimen with the support of his hemophilia care team

"RECOVERY WAS TOUGH, BUT I LEARNED I HAD MORE SUPPORT THAN *I THOUGHT POSSIBLE*."

HELLO FACTOR

Read stories like James' in *Hello Factor* magazine:
BleedingDisorders.com



Takeda

NEWS

Ask the Doctor - Marion Koerper MD

Q. My grandfather has hemophilia and I am pregnant with my first child, a boy and it is unknown if I am a carrier. What are the chances of my son being born with hemophilia?

A. Since your grandfather has hemophilia, your mother is an obligate carrier—she has to be a carrier because she got the X chromosome carrying the hemophilia gene from her father (your grandfather). This means that with every pregnancy of a boy, there is a 50% chance that her son (your brother) would have hemophilia. There is also a 50% chance that you got your mother's hemophilia-gene X chromosome; since you are pregnant with a boy, there is a 50% chance that he has hemophilia if you are a carrier. I recommend you contact the adult hemophilia center (HTC) at UCSF to get tested for carrier status as quickly as possible so that you and your obstetrician will know and can plan for a safe delivery of your baby.

There are 3 ways to determine if you are a carrier:

1. Family Tree—I have already explained your chances based on your family tree, it is 50% in your case.
2. Your clotting factor level—if it is low, you are a carrier. This will be difficult to determine now because you are pregnant, and your level now could be high because of pregnancy hormones. This is why you need to go to an HTC where they have experience interpreting results in pregnant women.
3. DNA analysis—in order to do this test quickly, your brother's DNA results would need to be available to the UCSF HTC. Did you or your brother participate in NHF's project MY LIFE/ OUR FUTURE in which you would have had your DNA analysis done? If so, the UCSF HTC will need your brother's permission to get his results. If not, your brother's blood would need to be drawn as well as yours. The analysis of your samples could take 1-2 months.

I hope these options are understandable to you. This analysis is complicated and the reason that you need to go to an HTC such as UCSF that has experience in dealing with these testing options.

Good luck!

Marion Koerper MD
Medical Advisor, HFNC
Past Director, UCSF HTC
Professor emerita, UCSF,
Dept of Pediatric Hematology
marionkoerper@sbcglobal.net

Guidelines for Emergency Department Management of Individuals with Hemophilia and Other Bleeding Disorders

IMPORTANT! (SEE DR. MARION KOERPER'S COMMENTS AT THE END)

The document was approved by the Medical and Scientific Advisory Council (MASAC) of the National Hemophilia Foundation (NHF) on December 2, 2019, and adopted by the NHF Board of Directors on December 5, 2019. Patients with bleeding disorders who present to an emergency department for care should receive appropriate, expeditious management. To this end, MASAC has developed the following guidelines. **Triage**

1) Individuals with bleeding disorders should be triaged urgently as delays in administering appropriate therapy, such as infusion of factor concentrate, can significantly affect morbidity and mortality.

2) Consultation with the patient's primary provider of bleeding disorder care, in most cases a hematologist, is strongly advised. If this provider is unavailable, consultation with a bleeding disorders provider from the closest hemophilia treatment center is recommended. Administration of clotting factor replacement to the patient should not be delayed waiting for a consultation. **Assessment 1**) Treatment for a suspected bleeding episode is based on clinical history. Physical exam findings may be normal in the early phases of most bleeding episodes associated with an underlying bleeding disorder. Spontaneous bleeding is common in those with severe disease (baseline factor levels <1%). When in doubt, administer clotting factor replacement therapy immediately.

2) Treatment decisions should be based on the ***suspicion*** of a bleeding-related problem, not the documentation of one.

3) If the patient or the parent of a patient suspects that occult bleeding is occurring, administer clotting factor replacement. Patients often are instructed to carry with them appropriate factor replacement dosing guidelines as advised by their treating hematologist. **Diagnostic Studies 1**) Clotting factor replacement therapy should be given ***before*** any diagnostic studies (X-rays, CT scans etc.) are performed to evaluate a suspected bleeding problem, especially in the case of head trauma or suspected intracranial hemorrhage. For routine joint bleeding, ***no*** radiographic studies are indicated. 2) For patients with hemophilia who have illnesses or disorders that necessitate an invasive procedure (lumbar puncture, arterial blood gas, arthrocentesis, etc.) or surgery, factor replacement therapy or bypass therapy to 100% must be administered in the emergency department ***prior to*** the planned procedure or surgery. In this situation, consultation with a hematologist is strongly recommended. 3) For an individual with known hemophilia, routine laboratory studies (PT, aPTT, factor levels), are not indicated in the treatment of a routine bleeding episode unless requested by the patient's hematologist. Treatment should not be delayed waiting for test results which may take several hours. In some cases, screening assays such as the aPTT and factor activity assays will not be accurate depending on the product the patient is taking and/or the reagents used for the assays at the local laboratory. The clinical severity of a patient's hemophilia is gauged by his or her baseline clotting factor level, a value that remains fairly constant throughout that person's life.

Indications for Factor Replacement Therapy include:

1) Suspected bleeding into a joint or muscle.

2) Any significant injury to the head, neck, mouth or eyes or evidence of bleeding in these areas.

3) Any new or unusual headache, particularly one following trauma.

4) Severe pain or swelling at any site.

5) All open wounds requiring surgical closure, wound adhesive, or steri-strips.

6) History of an accident or trauma that might result in internal bleeding.

7) Any invasive procedure or surgery.

8) Heavy or persistent bleeding from any site.

9) Gastrointestinal bleeding leading to moderate to severe anemia.

10) Acute fractures, dislocations and sprains.

11) Heavy menstrual bleeding leading to moderate to severe anemia or volume instability.

Continued on Page 12

Treatment *Hemophilia A without Inhibitor* The treatment of choice for individuals with hemophilia A (factor VIII deficiency) is recombinant factor VIII or the patient's product of choice. Plasma-derived concentrate is a suitable alternative in an emergency situation when recombinant factor VIII is not available. Cryoprecipitate and fresh frozen plasma are no longer recommended for treatment of individuals with hemophilia A. When bleeding is severe, the appropriate dose of factor VIII is **50 units/kg**. This should result in a factor VIII level of 80-100%. In individuals with hemophilia A receiving prophylaxis with emicizumab who present with acute bleeds, factor VIII should be given, as above. While emicizumab is effective in preventing (prophylaxis) bleeds, it is ineffective in treating acute bleeding events. No adjustment in factor VIII concentrate dosing is recommended for those patients on emicizumab. ***Mild Hemophilia A with Non-Life or Limb Threatening Bleeding*** Individuals with mild hemophilia A (baseline factor VIII greater than 5% and less than 50%) who are experiencing non-life or limb threatening bleeding may respond to desmopressin (DDAVP, see dosing recommendations below). This therapy should be used only if there is documentation in the medical record demonstrating a hemostatic response to this medication. Otherwise, treatment is the same as for other individuals with hemophilia A. ***Hemophilia B without Inhibitor*** The treatment of choice for individuals with hemophilia B (factor IX deficiency) is recombinant factor IX or the patient's product of choice. Plasma-derived concentrate is a suitable alternative in an emergency situation when recombinant factor IX is not available. Fresh frozen plasma is no longer recommended for treatment of individuals with hemophilia B. Cryoprecipitate does not contain factor IX. When bleeding is severe, the appropriate dose of factor IX is **100-140 units/kg**. This should result in a factor IX level of 80-100%. ***Hemophilia A or B with inhibitor*** **For individuals with inhibitors (antibodies to factor VIII or IX), treatment decisions may be more complicated. The care of inhibitor patients should be urgently discussed with the patient's hematologist. If an individual with an inhibitor presents in a life- or limb threatening scenario, the safest immediate action is to prescribe recombinant factor VIIa (rFVIIa) at a dose of 90 mcg/kg or activated prothrombin complex concentrates (FEIBA) at 75-100 units/kg.* The patient or family can also provide information on response to these therapeutic bypassing agents. * Note:** rFVIIa is recommended over FEIBA for acute bleeding events or procedures in hemophilia A inhibitor patients on emicizumab prophylaxis as aPCCs may cause thrombosis or thrombotic microangiopathy in those receiving emicizumab and should be avoided. *** Note**: In factor IX patients with a history of inhibitors and anaphylaxis, factor IX-containing products, including FEIBA should be avoided. **Additional treatment considerations**:

1) If a patient with hemophilia or other bleeding disorder or the parent of a patient with a bleeding disorder brings clotting factor concentrate with them to the emergency department, allow them to utilize it. This recommendation acknowledges many emergency rooms do not have the majority of (or any) clotting factor concentrates on formulary. Patients or family members should be permitted to reconstitute the product and administer it whenever possible. Individuals with bleeding disorders are encouraged to have an emergency dose of factor concentrate or DDAVP (in the form of intranasal Stimate®) in their home and to take it with them when they travel. In those situations when a patient does not bring their own clotting factor concentrate, emergency departments must be prepared to provide clotting factor replacement. Emergency departments must have ready access to factor replacement products so that they are available within one hour of the patient's arrival. In the situation where hospital formulary factor concentrate is used, in order to expedite care, emergency department providers should order ***unreconstituted*** factor concentrate from their pharmacy or blood bank and reconstitute the product in the emergency department.

2) Factor replacement must be administered intravenously by IV push over 1-2 minutes or per label instructions.

3) The factor dose should be ordered as "up to the closest vial contents." The full content of each reconstituted vial should be infused, since a moderate excess of factor concentrate will not create a hypercoagulable state but will prolong the therapeutic level of the product administered; thus, it is prudent to "round up."

4) When treating an individual with mild hemophilia A who is responsive to DDAVP, the dose and prior responsiveness are usually known. The dose of DDAVP is 0.3 micrograms/kg subcutaneously or intravenously in 30 ml normal saline over 15-30 minutes. It may also be administered as a concentrated nasal spray "Stimate®" at a dose of 1 spray in one nostril for individuals <50 kg and 1 spray in each nostril for individuals >50 kg.

5) The most experienced IV therapist or phlebotomist should perform venipunctures. Traumatic venipunctures and repeated needle sticks cause painful hematomas that may limit further IV access.

6) In any suspected bleeding emergency in which the clotting factor level of a patient with hemophilia is unknown, the factor level should be assumed to be 0%.

Continued on Page 13

7) Intramuscular injections, including immunizations, should be avoided whenever possible. If they must be given, factor replacement therapy must precede the injection. (It can be timed following a prophylactic dose of clotting factor concentrate. This is not required when vaccination is given subcutaneously).

8) In situations in which patients are hemodynamically stable and are not requiring volume replacement, the smallest gauge needle should be utilized for obtaining IV access (25g butterfly needles in young infants, 23g butterfly needles in older children and adults)

9) Tourniquets should not be applied tightly to extremities because they may cause bleeding.

10) Aspirin and aspirin-containing products should be avoided in individuals with hemophilia unless there is a cardiac indication, and then only under close observation for bleeding, e.g. monitoring hemoglobin levels. Acetaminophen and/or oral opioids may be used for analgesia. Non-steroidal anti-inflammatory (NSAID) drugs may be carefully administered to select patients, such as individuals with chronic arthritic pain who are not actively bleeding or being treated for a recent bleeding problem. 11) If a patient with hemophilia is bleeding and requires transportation to another facility for definitive care, all efforts should be made to replace the deficient clotting factor ***before*** transport.

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Dr Koerper' comments In December 2019 MASAC issued this revised version of their recommendations for management of individuals with bleeding disorders who are being seen in an Emergency Room. We recommend that you make a copy for your physician and a copy to take to the ER to give to the treating MD in the ER. Bear in mind that most ER doctors are unfamiliar with the treatment of individuals with bleeding disorders, and most ER Pharmacies do not stock most clotting factor concentrates unless they are affiliated with a Hemophilia Treatment Center (HTC). In order to avoid treatment problems in an ER, besides, taking this document, we make the following recommendations;

1. Enroll in your closest HTC.The CDC website has a list of all US HTCs, so you can find the one that is closest to you.

2. Once enrolled, talk to the hematologist about your diagnosis and what treatment option is best for you. 3. From the HTC nurse, learn how to give your treatment product, either intravenously, subcutaneously or intranasally, depending on the product.

4. Enroll in the HTC Home Delivery Program and order 2-4 doses of the agreed upon

treatment product to be delivered to you to keep on hand in case of emergency.

5. Obtain from the HTC Hematologist a treatment letter that states your name, birthday, diagnosis, preferred treatment product, and dose. The letter should also include a 24-hour phone number that you and the ER doctor can use to reach the hematologist on call to confirm this information and discuss your current problem.

6. Call the 24-hour on call hematologist if you are unsure whether to go to the ER and which ER to go to.

7. If you are advised by the hematology staff to go to the ER, take a copy of these MASAC

recommendations, and the letter from your hematologist. Also, take at least 4 doses of your treatment product to be used in the ER if they do not have any doses on hand.

8. Be sure that a dose of the treatment product is given before any procedure, such as

lumbar puncture (LP), IM injection, head scan, or any surgery. 9. If you are not comfortable with your care, call your 24-hour hematology number.

SAVE THE DATE

THE FEMALE FACTOR
affected and connected

*FEMALES AFFECTED AND CONNECTED

ARE YOU READY FOR SOMETHING COMPLETELY DIFFERENT?

GET READY THIS YEAR TO RETREAT AT HOME!

**"NEVER BEFORE SEEN' GIVE-AWAYS FOR THE FIRST 60 REGISTRANTS!

Registration opens soon at hemofoundation.org

*Female/female identifying, ages 12 & up

**Must reside in State of California to receive Give-A-Ways

Join The Female Factor Facebook group!!

Find THE FEMALE FACTOR affected and connected on

Find The Hemophilia Foundation of Northern California FOR ALL BLEEDING DISORDERS on

QUESTION CORNER

HFNC and Your Personal Information

Hemophilia Foundation of Northern California (HFNC) collects personal information from its community members in order to communicate about Foundation events, activities and services. Our primary purpose for collecting this information is to contact you regarding programs such as Camp Hemotion, Family Education Day, The Female Factor and others.

We take our responsibility to protect your personal information seriously and work constantly to improve our systems and processes including communicating our information protection policies to all relevant parties.

QUESTION: What information does HFNC collect?

ANSWER: We primarily collect contact information such as name, address, phone number, email and the like. Additionally, we collect information regarding bleeding disorder types and your community connection (E.g. Parent, carrier, sibling, etc.). This helps us focus our communications to you. It provides HFNC with an accurate census of the community. It also helps make sure that we don't bombard your eight-year old with requests for donations or invite your grandpa to our youth camp.

This general contact information resides in our database powered by Bloomerang. Bloomerang is a popular community management software tool used by many other bleeding disorder chapters.

QUESTION: Does the Foundation collect medical records or data?

ANSWER: The Foundation does not collect or maintain individual medical records of any kind for use in day-to-day Foundation business. However, HFNC utilizes a secure database with a software called DocNetwork (aka Camp Docs), a well known software used by schools and camps around the country. We use Camp Docs to collect medical information required by infirmary staff to keep your children safe at Camp Hemotion. This data resides separate from our day-to-day database with Bloomerang. The medical information is only accessible by infirmary or foundation staff.

Some of us remember when paper applications with medical data were kept at the Foundation. This is no longer the case!

QUESTION: Who has access to my personal information?

ANSWER: HFNC does not sell your personal information to any organization and uses information for the purpose of contacting you about events and activities. HFNC also receives advertising revenue from industry partners who may want to send marketing materials to community members on our mailing list. In such cases, HFNC staff and/or volunteers prepare the mailing. Your information is never provided to any company or organization.

The Foundation can only be successful with the help of our many volunteers. We recognize that some of our volunteers also work in industry. For that reason, all volunteers are required to sign a Code of Conduct. This clearly spells out that any contact information can ONLY be used in the course of conducting specific Foundation business. It cannot be collected or kept by any volunteer, or used in any way, or at any other time or location. HFNC has a zero tolerance policy for violations of our policy and will investigate reported violations. For example, volunteers from one of our programs such as Camp Hemotion or Family Camp may help us get the word out regarding upcoming activities. HFNC also utilizes volunteers for specific community outreach programs.

No actual patients depicted.

ADYNOVATE
[Antihemophilic Factor (Recombinant), PEGylated]

REAL LIFE. REAL BLEED PROTECTION.*

AdynovateRealLife.com

HEMOPHILIA A IS A PIECE OF YOU.

NOT ALL OF YOU.

ADYNOVATE® is a treatment that can be personalized to fit your lifestyle so you have more time to spend doing the other things that also make you, you. It has a simple, twice-weekly dosing schedule on the same 2 days every week.[1,2]

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

ADYNOVATE twice-weekly prophylaxis prevented or reduced the number of bleeds[2]

ADYNOVATE was proven in 2 pivotal clinical trials to prevent or reduce the number of bleeding episodes in children and adults when used regularly (prophylaxis)[2]

- **Children Under 12 Years**: This study evaluated the efficacy of ADYNOVATE twice-weekly prophylaxis and determined the ability to treat bleeding episodes for 6 months in 66 children under 12 years old who received 40–60 IU/kg of ADYNOVATE prophylaxis treatment[2]
  - During the 6-month study in children under 12, those receiving twice-weekly prophylaxis treatment experienced a median† overall ABR‡ of 2.0
  - 0 bleeds in 38% (25 out of 66 patients) during 6 months on twice-weekly prophylaxis
- **Adolescents and Adults 12 Years and Older**: This study evaluated the efficacy of ADYNOVATE in a 6-month study that compared the efficacy of a twice-weekly prophylactic regimen with on-demand treatment and determined hemostatic efficacy in the treatment of bleeding episodes in 137 patients. These adolescents and adults were given either ADYNOVATE prophylaxis twice-weekly at a dose of 40–50 IU/kg (120 patients) or on-demand treatment with ADYNOVATE at a dose of 10–60 IU/kg (17 patients). The primary study goal was to compare ABR between the prophylaxis and on-demand treatment groups[2]
  - 95% reduction in median overall ABR (41.5 median ABR with on-demand [17 patients] vs 1.9 median ABR with prophylaxis [120 patients])
  - 0 bleeds in 40% (40 out of 101 per-protocol§ patients) during 6 months on twice-weekly prophylaxis

†Median is defined as the middle number in a list of numbers arranged in numerical order.
‡ABR=annualized bleed rate, the number of bleeds that occur over a year.
§Per-protocol patients were assigned to the prophylactic group and treated with their originally assigned dose for the entire duration of the study.

ADYNOVATE Important Information

What is ADYNOVATE?

- ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital factor VIII deficiency).
- Your healthcare provider (HCP) may give you ADYNOVATE when you have surgery.
- ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADYNOVATE?

Do not use ADYNOVATE if you:

- Are allergic to mouse or hamster protein.
- Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)].

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

What should I tell my HCP before using ADYNOVATE?

Tell your HCP 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 ADYNOVATE passes into your milk and if it can harm your baby.
- Are or become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

What important information do I need to know about ADYNOVATE?

- You can have an allergic reaction to ADYNOVATE. 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, lightheadedness, dizziness, nausea or fainting.
- Do not attempt to infuse yourself with ADYNOVATE unless you have been taught by your HCP or hemophilia center.

What else should I know about ADYNOVATE and Hemophilia A?

- Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE 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 are possible side effects of ADYNOVATE?

- The common side effects of ADYNOVATE are headache and nausea. These are not all the possible side effects with ADYNOVATE. Tell your HCP about any side effects that bother you or do not go away.

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 ADYNOVATE on the following page and discuss with your HCP.

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

References: 1. Valentino LA. Considerations in individualizing prophylaxis in patients with haemophilia A. *Haemophilia.* 2014;20(5):607-615. **2**. ADYNOVATE Prescribing Information.

S49399 08/19

Takeda

ADYNOVATE
[Antihemophilic Factor (Recombinant), PEGylated]

Patient Important facts about

ADYNOVATE® [Antihemophilic Factor (Recombinant), PEGylated]

This leaflet summarizes important information about ADYNOVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADYNOVATE. If you have any questions after reading this, ask your healthcare provider.

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

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

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

What is ADYNOVATE?

ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

Who should not use ADYNOVATE?

You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)]

Tell your healthcare provider if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

How should I use ADYNOVATE?

ADYNOVATE is given directly into the bloodstream.

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

Your healthcare provider will tell you how much ADYNOVATE to use based on your individual weight, level of physical activity, the severity of your hemophilia A, and where you are bleeding.

Reconstituted product (after mixing dry product with wet diluent) must be used within 3 hours and cannot be stored or refrigerated. Discard any ADYNOVATE left in the vial at the end of your infusion as directed by your healthcare professional.

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

How should I use ADYNOVATE? (cont'd)

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

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

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 ADYNOVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

What are the possible side effects of ADYNOVATE?

You can have an allergic reaction to ADYNOVATE.

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, lightheadedness, dizziness, nausea or fainting.

The common side effects of ADYNOVATE are headache and nausea. 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 ADYNOVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADYNOVATE and Hemophilia A?

Your body may form inhibitors to Factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE 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 ADYNOVATE for a condition for which it is not prescribed. Do not share ADYNOVATE 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 ADYNOVATE. The FDA-approved product labeling can be found at www.ADYNOVATE.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.

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HFNC PRESENTS

Unite
for Bleeding Disorders

Saturday, October 10, 2020

Unite for Bleeding Disorders will occur in over 40 cities across the country to raise funds and awareness for local chapters. The funds raised through this event will serve families in Northern California

START OR JOIN A TEAM TODAY!

Register at www.uniteforbleedingdisorders.org

CALENDAR

AUG		
8/5/20-8/8/20	NHF BDC	Virtual
8/14/20	HCC Policy Summit	Sacramento, CA
8/24/20-8/29/20	HFA Symposium	Virtual
SEPT		
9/7/20	Labor Day	
9/18/20-9/19/20	Famlia de Sangre	Virtual
OCT		
10/10/20	Unite Walk	Virtual
10/18/20	Family Education Day	Virtual
NOV		
11/11/20	Veteran's Day	
11/13/20-11/14/20	The Female Factor Retreat	Virtual
TBD	NHF Insurance Reimbursement Summit	Baltimore, MD
11/26/20-11/27/20	Thanksgiving Holiday	
DEC		
12/1/20	World AIDS Day	
12/1/20	Giving Tuesday/ End of Year Event	Virtual
12/25/20	Christmas Day	
12/31/20	New Year's Eve	

HOME CHAPTER ORGANIZATION

HFNC Hemophilia Foundation of Northern California
https://www.hemofoundation.org/
Auxiliary Fresno
Auxiliary San Jose

AFFILIATED ORGANIZATIONS

NHF National Hemophilia Foundation
https://www.hemophilia.org/
NHF Chapters (See full list at NHF):

HFSC Hemophilia Foundation of Southern California
http://www.hemosocal.org/

HASDC Hemophilia Association of San Diego County
http://hasdc.org/

CCHF Central California Hemophilia Foundation
https://www.cchfsac.org/

AHA Arizona Hemophilia Association
https://www.arizonahemophilia.org/

HFO Hemophilia Foundation of Oregon
http://hemophiliaoregon.org/

HFA Hemophilia Federation of America
http://www.hemophiliafed.org/

HCC Hemophilia Council of California
https://www.hemophiliaca.org/

WFH World Federation of Hemophilia
https://www.wfh.org/

PARTNER ORGANIZATIONS

HTC Hemophilia Treatment Centers:
Stanford University Medical Center
https://www.stanfordchildrens.org/en/service/hematology
University of California at Davis
https://www.ucdmc.ucdavis.edu/hemophilia/
University of California San Francisco
https://www.ucsfhealth.org/clinics/hemophiliatreatment_center/
UCSF Benioff Children's Hospital Oakland
https://www.childrenshospitaloakland.org
Valley Children's Hospital
https://www.valleychildrens.org/

MFTC Music for the Cause
https://www.musicforthecause.org/

Hemophilia Foundation
of Northern California
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Emeryville, CA 94608

The Hemophilia Foundation of Northern California
FOR ALL BLEEDING DISORDERS

The Hemophilia Foundation of Northern California (HFNC) does not endorse any particular pharmaceutical manufacturer or home care company.

PLEASE NOTE: The companies whose advertisements are listed herein have purchased this space, and are NEVER provided with members' names, addresses or any other personal details. Paid advertisements and paid inserts should not be interpreted as a recommendation from HFNC, nor do we accept responsibility for the accuracy of any claims made by paid advertisements or paid inserts.

Since we do not engage in the practice of medicine, we always recommend that you consult a physician before pursuing any course of treatment.

Information and opinions expressed in this publication are not necessarily, those of the Hemophilia Foundation of Northern California, or those of the editorial staff.

Hemophilia Foundation of Northern California is a 501(c)(3) non-profit. Donations are tax-deductible, much needed and appreciated.

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Visit our website at www.hemofoundation.org for important information.
If you would like to advertise in the next issue, please contact the foundation.