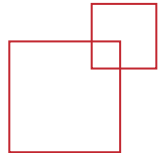


# HEMOPHILIA ACTION

A PUBLICATION OF THE HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA

VOLUME 17 | ISSUE 1 | WINTER | 2021

## FAMILY INFO DAY



Virtual Family Info Day 2020 (HFSC Annual Day) took place in October with over 100 families joining us to learn about key educational updates and HFSC news. Thank you to all who attended, we miss you!

Community members soaked in complicated cytokine cascade instruction from the renowned Dr. Diane Nugent from CIBD who gave the remarkable keynote address, a "Brief Review of Everything." Following were our amazing session speakers, Dr. Mauricio Silva presenting on Joint Health (en español), Dr. Roach and Dr. Quon presenting on IV Infusion, and Debbie de la Riva presenting on mental health. Remaining connected and providing peer support are so important.

We also recognized and congratulated our brilliant scholarship winners and 2020 Award Winners: Medical Provider: Dr. Diane Nugent; Advocacy Award: Andrew Yu; Volunteer Award: Karen Yang; Fundraiser Award: Rose Cardenas. THANK YOU!

All attendees received a box of booth giveaways and branded HFSC face masks for their entire family! See you on May 22, 2021 for our next HFSC Annual Day!

Big Shout out to Platinum Sponsor Takeda, Gold Sponsors Genentech and Octapharma, and Silver Sponsors BioMarin, CSL Behring, Pfizer, Sanofi, Spark Therapeutics and uniQure!



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*Donations made between 11.1.20 – 12.31.20*

## 2021 CALENDAR

**emPOWERment and World  
Hemophilia Day Celebration**  
April 17

**BRO Check In and Chat:  
Coping with Covid Isolation**  
April 21

**Virtual Community Dinner: Crear  
Conexiones: buscar apoyo en un  
momento de distanciamiento social**  
April 28

**Virtual Annual Meeting  
(Family Information Day)**  
May 22

## HEMOPHILIACTION

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## A LETTER FROM THE BOARD PRESIDENT

I hope many of you had the chance to attend the Industry Forum a few weeks ago. Our staff does a tremendous job with these events, whether they are in person or virtual. I popped into several sessions that I found very informative, and I hope you did too. Coming up next, we have empowerment Forum and World Hemophilia Day, which will take place virtually on Saturday, April 17. If you haven't signed up yet, please do so as soon as possible.

On the topic of education and support, I recently had the opportunity to watch a movie called "Crip Camp" on Netflix which discussed the passage of Section 504 of the Civil Rights Act, as well as the Americans with Disabilities Act. If you have never had the chance to watch this movie, I highly recommend it. The movie started out by showing a camp for children with disabilities in the 1970's and the tremendous impact the camp had on the campers' lives. Several years later, this same group of people worked together to pass the legislation mentioned above. This movie reminded me of all those in the bleeding disorders community who have come before us and created the wonderful support systems we have in place today. I can't imagine navigating the world of bleeding disorders without our

local and national foundations, as well as our Hemophilia Treatment Centers and The Painted Turtle Camp. As my term as President of the Hemophilia Foundation of Southern California comes to an end, and we welcome Rick Kelly as our new President, I am proud to have worked with such an amazing and dedicated group of people as the staff and fellow Board Members of the Hemophilia Foundation of Southern California. - *Sandy Knight, Esq.*

## A LETTER FROM THE EXECUTIVE DIRECTOR

I am so overwhelmed with your resilience and strength during this time. So many of you are making a tremendous effort to join us on Zoom at our events. For me, I suppose, "seeing you" at least virtually is better than not connecting with you at all! I wanted to share that as of now, we will be meeting virtually at least through June. Our Board of Directors is continuously evaluating the COVID situation and whether it's safe for us to meet again live. Our hearts are broken for all of you who have suffered loss in your families from this horrific virus and please reach out to us if we can support you in any way. Speaking of the Board, I wanted to give a HUGE and heartfelt thank you to Sandy Knight who has incredibly served as our President for the last two years. She has worked so diligently behind the scenes taking us through challenges with COVID and providing valued wisdom and strategic direction to the Foundation and we are ever so thankful for her hard work, dedication, and passion. While she remains on the Board, I would also like to welcome our new Board President, Rick Kelly, whom many of you know and has already diligently worked on the Board for several years. As always, please email me at [michelle@hemosocal.org](mailto:michelle@hemosocal.org) with any thoughts or concerns, or call the office number at 626-765-6656!  
- *Michelle Kim, Esq.*



## HFSC WELCOMES BOARD PRESIDENT RICK KELLY, MBA

GO SEEK. GO EXPLORE.  
**GO AHEAD.**

PEOPLE LIKE YOU. STORIES LIKE YOURS.  
Explore more at [HEMLIBRAjourney.com](https://HEMLIBRAjourney.com)



**Discover your sense of go. Discover HEMLIBRA.**

#### What is HEMLIBRA?

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

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

**HEMLIBRA increases the potential for your blood to clot. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.**

#### These serious side effects include:

- **Thrombotic microangiopathy (TMA)**, a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- **Blood clots (thrombotic events)**, which may form in blood vessels in your arm, leg, lung, or head

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

  
**HEMLIBRA**<sup>®</sup>  
emicizumab-kxwh | 150  
injection for subcutaneous use | mg/mL

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



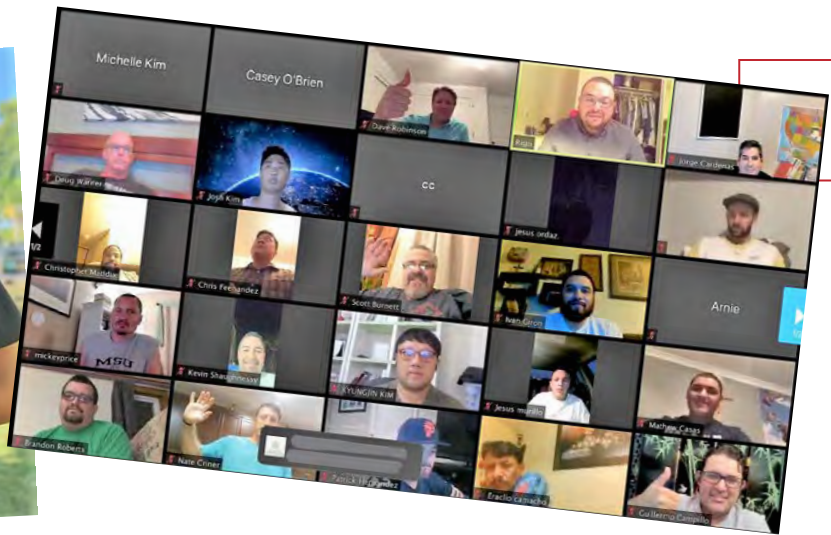
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# BLEEDERS REACHING OUT (BRO): OCTOBER MEETING



An extraordinary group of men gathered on October 8, 2020 to check in and chat with each other. The men were able to connect and share experiences on how they are coping with the pandemic! Thank you to Dave Robinson for moderating our talk, and Rigo Manzo for helping lead the group. BRO members in attendance also received a hat embroidered with the BRO logo.

Thank you to the Hemophilia Federation of America for its partnership and support!

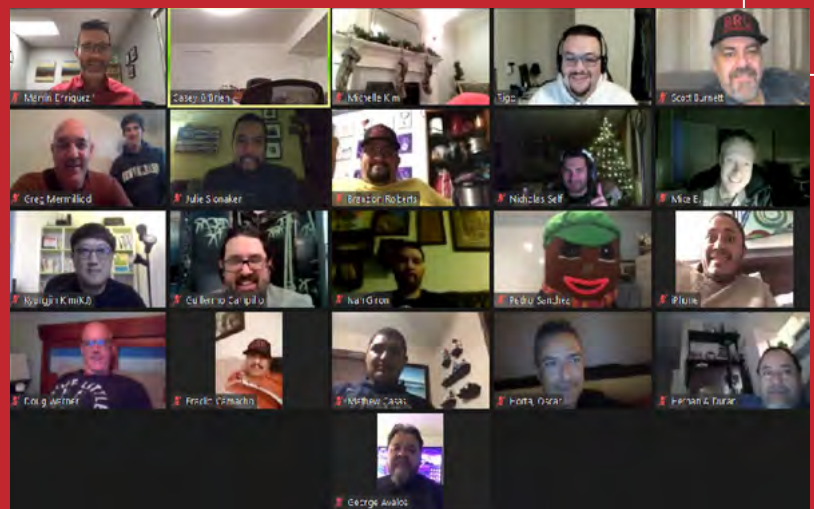


# BLEEDERS REACHING OUT (BRO): DECEMBER MEETING

Celebrating the holidays and sharing tips on how to de-stress, HFSC's BRO, a group of over 30 men, gathered on December 9, 2020 to check in with each other and connect. Thank you to the marvelous Marvin Enriquez for moderating our talk, Rigo Manzo for helping lead the group, and John Kim for providing "Tips to Enhance Your LinkedIn Profile and Job Search!"

Congratulations to our Wheel winners: Eraclio Camacho, Erwin Luu, and George Avalos! As a holiday gift, all men participating received a rosewood utility tool engraved with the BRO logo!

Thank you HFA for your partnership!



# SNOWFLAKE FESTIVAL

On December 5, 2020, HFSC hosted its virtual Snowflake Festival on Zoom for more than 100 families. Families gathered to watch a special presentation from a North Pole elf, played games, and enjoyed a special visit from Elsa and Santa! Attendees also listened to three teens speak about their advocacy experience and what it meant to them. Thank you to Haylee Slonaker, Ashrita Prathigudupu, and Nathan Mermilliod for sharing about your advocacy experiences!

The event ended with a holiday sing a long, and all children in attendance received a gift card. Thank you to Beyond Rec for putting together this amazing program! Thank you to our sponsors: CSL Behring, Genentech, Novo Nordisk, and Takeda.



Thank You To Our Sponsors



# 12TH ANNUAL UNITE FOR BLEEDING DISORDERS WALK



We are extremely grateful to everyone who donated, raised funds, and promoted awareness for HFSC's 12th Annual Unite for Bleeding Disorders All Star Virtual Walk on November 7! Although this year brought unprecedented challenges, and we couldn't be together for our live walk, HFSC's local community continues to be a constant source of support, raising nearly \$150,000 on behalf of advocacy and access to care, research, emergency financial assistance, scholarships, and Camp Blood Brothers & Sisters.

**Not only that, but we also came in 2nd place in funds raised out of all chapters in the country!**

More than 100 attendees joined the virtual walk on November 7 via Zoom and Facebook Live to play games, win prizes, and

hear from Academy Award-winning celebrities as well as our local community stars! A special thank you to Congressman Adam Schiff, Academy Award Winner Marlee Matlin, Actor Leith Burke, The Mandalorian, and Pops and Pun from The Painted Turtle for presenting at this event! And much gratitude to Amelie Iavicoli for singing the National Anthem, Elena Iavicoli for serving as Chair for the walk, and to all of our community stars for their participation!

Congratulations to our Top 10 Teams: Team Joshua Kim, Amelie's GT Striders, We Clot This, Trot to Clot for Kacen, Cole Train, Forrest Fighters, Team Avila, Perry Parker's Team, Team Follow the Yellow Brick Road, and Ortho Walkers.

Congratulations to our Top 10 Individuals: Michelle Kim, Rose Cardenas, Ashley Karnes, Amelie Iavicoli, Forrest Kelly, Jesus Avila, Michele Warner, Perry Parker, Doris Quon, and Valinda Linarez.

Thank you to our Local Sponsors! Gold: W.M. Keck Foundation and Novo Nordisk. Silver: Bayer, Center for Inherited Blood Disorders, CSL Behring, CVS, Genentech, Soleo Health, Sam's Club and Walmart. Bronze: Brothers Healthcare, BioMarin, Medexus Pharma, Octapharma, Oso Specialty Infusion Services, uniQure and Westmount Asset Management.

**GOAL \$140,000**



**\$149,667**  
RAISED

**253**  
PARTICIPANTS



Registration is now open for our 2021 walk, which will take place on November 6 at Griffith Park! Sign up by visiting [www.uniteforbleedingdisorders.org/event/socal](http://www.uniteforbleedingdisorders.org/event/socal) today.



# Preparing for Emergencies as a Young Adult With Hemophilia



For more information, scan the QR code with your smartphone camera to access *Young Adults and Hemophilia B*.



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During the journey to adulthood, you may find yourself with new obligations, and may learn new lessons about being on your own; this is all part of being independent. It can be difficult handling new responsibilities and uncertainties while living with a chronic condition. Being prepared for an emergency is part of transitioning to life as a young adult with hemophilia.

## Recognizing Emergency Situations

Though there may be no visible signs or symptoms, bleeding issues such as joint hemorrhages, head injuries, muscle bleeds, and trauma can be life-threatening. Emergency bleeding events require recognition and immediate intervention with factor replacement product.<sup>1</sup> **The following situations typically require factor replacement therapy:**

- Suspected bleeding in the brain, which is life-threatening and requires immediate emergency care<sup>2</sup>
- Suspected bleeding into a joint or muscle<sup>1</sup>
- Significant injury to the head, neck, mouth, or eyes, or evidence of bleeding in those areas<sup>1</sup>
- New or unusual headaches particularly following trauma<sup>1</sup>
- Severe pain or swelling at any location<sup>1</sup>
- Open wounds requiring surgical closure, wound adhesive, or bandages<sup>1</sup>
- History of an accident or trauma that might result in internal bleeding<sup>1</sup>
- Invasive procedure or surgery<sup>1</sup>
- Heavy or persistent bleeding from any site<sup>1</sup>
- Gastrointestinal bleeding<sup>1</sup>
- Heavy menstrual bleeding leading to moderate to severe anemia/volume instability

## Recognizing Emergency Situations (continued)

- Acute fractures, dislocations, and sprains<sup>1</sup>
- Limited motion, pain, or swelling of any area<sup>2</sup>

## Preparing for Emergency Care

It's important to think ahead regarding the need for factor before an emergency happens. This is an important aspect of hemophilia self-care.

**Take factor with you<sup>3</sup>:** Factor replacement therapy is used for patients with hemophilia for acute bleeding episodes or presumed acute bleeding episodes.<sup>4,5</sup>

**Keep an emergency dose of clotting factor concentrate in your home<sup>1</sup>:** Clotting factor concentrates might not be available at some hospitals. If you do not have factor with you, and are advised by your hemophilia treatment center to go to the hospital, the emergency department (ED) personnel may have to identify another hospital to best deal with the emergency, which could delay treatment.

**Take factor with you when you travel and/or if you go to the ED<sup>1,3</sup>:** ED personnel may ask if you have your factor with you, and they may ask you to infuse the dose yourself.

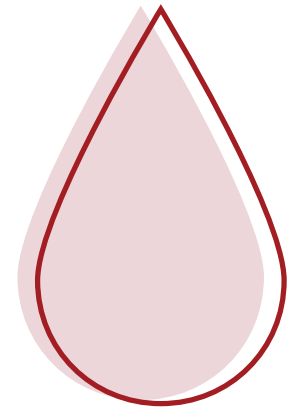
## Personal Empowerment

The transition from living with your parents to being on your own can be both exhilarating and overwhelming. The education and advice you receive may help prepare you to handle both everyday events as well as emergencies that may occur. Important components of leading an active lifestyle with hemophilia include prompt treatment of bleeds, staying in contact with your HTC and adopting healthy habits.

**References:** **1.** National Hemophilia Foundation (NHF). MASAC document #257. Guidelines for emergency department management of individuals with hemophilia and other bleeding disorders. New York, NY: National Hemophilia Foundation (NHF); 2019. <https://www.hemophilia.org/Researchers-Healthcare-Providers/Medical-and-Scientific-Advisory-Council-MASAC/MASAC-Recommendations/Guidelines-for-Emergency-Department-Management-of-Individuals-with-Hemophilia-and-Other-Bleeding-Disorders>. Accessed May 10, 2020. **2.** National Institutes of Health (NIH). National Heart, Lung, and Blood Institute (NHLBI). Living with hemophilia. NHLBI.NIH.gov Web site. <https://www.nhlbi.nih.gov/health-topics/bleeding-disorders>. Updated September 11, 2019. Accessed May 10, 2020. **3.** Morris C. The Emergency Room: Prepare to Succeed. A Guide to the ER for Persons with Bleeding Disorders. Montreal, Quebec: Canadian Hemophilia Society (CHS); 2018. <http://www.hemophilia.ca/files/er2.pdf>. Accessed May 10, 2020. **4.** National Hemophilia Foundation (NHF). Hemophilia B. Hemophilia.org Web site. <https://www.hemophilia.org/Bleeding-Disorders/Types-of-Bleeding-Disorders/Hemophilia-B>. 2020. Accessed May 10, 2020. **5.** Moake JL. Coagulation Disorders: Hemophilia. Kenilworth, NJ: Merck & Co., Inc.; 2020. <https://www.merckmanuals.com/professional/hematology-and-oncology/coagulation-disorders/hemophilia>. Accessed May 10, 2020.



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# ASH ISTH NHF WFH Guideline Recommendations for the Diagnosis of von Willebrand Disease (VWD)



## What it covers

- Evidence-based guidelines intending to improve accurate diagnosis of von Willebrand Disease (VWD), minimize inappropriate testing and avoid harms from over-diagnosis.



## Why it matters

- VWD is the most common inherited bleeding disorder, yet accurate and timely diagnosis is challenging.
- Current barriers to accurate diagnosis of VWD include:
 

A lack of understanding of the difference between normal and abnormal bleeding symptoms.	A lack of/limited availability and expertise for specialized lab testing.
--	---
- It is important to improve accurate diagnosis to ensure access to care and minimize inappropriate testing and harms caused from over-diagnosis.



## Who it affects

- **Hematologists, General Practitioners, Internists, Obstetricians, Gynecologists**  
Health care professionals who provide screening for patients to accurately diagnose VWD.
- **Individuals who may be experiencing abnormal bleeding who should be evaluated for VWD**  
Symptoms can disproportionately affect women, who may experience menstrual and postpartum hemorrhage.



## What are the highlights

- Call to improve education around the value and use of bleeding assessment tools (BATs).
 

BATs are recommended as an initial screening tool for patients with a low probability of VWD (e.g., those seen in the primary care setting).	BATs are NOT recommended as a screening tool to decide whether to order specific blood testing for patients with intermediate/high probability of VWD (e.g., those referred to a hematologist or those with an affected first-degree relative).
--	---
- New recommendations suggest broadening the classification of VWD to be more inclusive of individuals who experience VWD-like bleeding but whose von Willebrand factor (VWF) levels used to confirm diagnosis of type 1 VWD do not meet the previously proposed diagnostic threshold of 30% or less.
- Suggestion to change the approach for a type 1 VWD patient with normalized VWF levels over time, specifically to reconsider diagnosis as opposed to removing diagnosis.
- Recommendations to use targeted genetic testing to diagnose type 2B VWD.

**Total number of panel recommendations: 11**

**Reference:** James PD, Connell NT, Ameer B, et al. ASH ISTH NHF WFH 2021 guidelines on the diagnosis of von Willebrand disease. *Blood Adv.* 2021;5(1):280-300.

For more information on the ASH ISTH NHF WFH Clinical Practice Guidelines on von Willebrand Disease, visit <https://ashpublications.org/bloodadvances/pages/vwd-guidelines>.

## COMMUNITY SPOTLIGHT: JARETT GUILLOW



Hello, all! My name is Jarett Guillow, I am 24 years old and was diagnosed with moderate Hemophilia B when I was born. I have been a part of the Hemophilia Foundation of Southern California for as long as I can remember. I attend as many events as possible and love talking with new families! In particular, I love talking with camp age individuals about The Painted Turtle camp. Growing up in the community has made me so indebted to not only the foundation, but also to all my fellow patients. Because of this, I wished to inform all of you of a major update in my life. I have been accepted into medical school for the class of 2025! It is in large part thanks to the foundation and this community that I have been able to pursue my dream all these years. To give a more complete view of my journey thus far; I graduated from Chapman University Cum Laude with a Bachelor's of Science Degree in Biochemistry and Molecular Biology with a minor in mathematics in 2019 and again graduated Summa Cum Laude with a Master's Degree in Computational and Data Sciences with a biological emphasis in 2020. During my master's program I did research into complex computational docking models of prostate cancer treatment in attempts to verify a mechanism of action and improve cancer therapy. During my undergraduate years, I was a 4 year NCAA DII swimmer while also working as a tutor and Supplemental Instructor for calculus. Once I began my master's degree, I worked for the university as the instructor of record for multiple courses of calculus which I have continued to teach at the collegiate level even now during

my gap year. While I still have a long journey in front of me, I am hopeful to become a pediatric hematologist/oncologist. With my continued education, I hope to be able to give back to our community and be involved more and more with foundation events and camp sessions. I am especially thankful to Michelle Kim and the rest of the foundation staff who have guided me for these many years and without whom, I would not have been able to reach this point of my life goals. Despite the time commitments of medical school, I still wish to be able to impart whatever I can towards others who have similar aspirations as myself. If you want to learn more about college and medical school and don't know who to turn to, I am happy to talk about my experiences and give my advice!

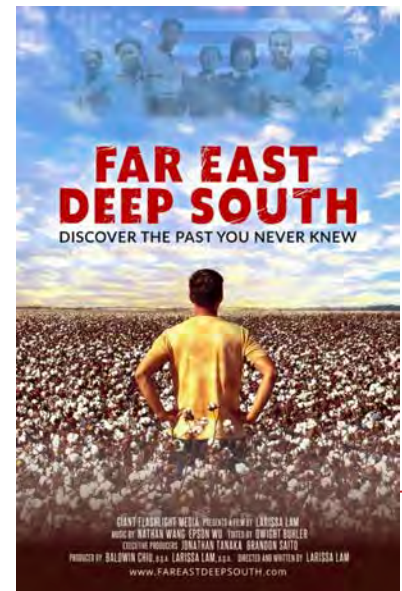
## COMMUNITY SPOTLIGHT: BALDWIN CHIU

My name is Baldwin Chiu and I have Factor 7 deficiency. We found out because when I was little, my nose would bleed for hours and I'd have to go to the hospital to get it cauterized to stop the bleeding. I accidentally ran into Hemo SoCal because the office was right next to my doctor's office. Michelle and the office team were so kind to tell me all about the organization and invited me in. When I told them that I was beginning to produce films, they told me about the Dr. Earl James Fahringer Performing Arts Scholarship. I applied since I was enrolling into the Act One Producing program. I was thrilled to receive the scholarship and it confirmed that I should leave my engineering job to pursue my passion in arts and entertainment.

The Act One Producing program prepared me to make and finish our new documentary film, Far East Deep South. The film is about a Chinese-American family's search for their roots which leads them to Mississippi, where they stumble upon surprising family revelations and uncover the racially complex history of the early Chinese in the segregated South during the Chinese Exclusion era.

Due to COVID, our 2020 release had some major changes. It's been a very tough year, but we still got into 11 virtual film festivals, winning 5 of them. The film is now being distributed to schools across the country with Stanford University being the first to license it. Now the stage is set in 2021 for the PBS broadcast. We are so thankful for the support of Hemo SoCal and of course HAD to include "Hemophilia Foundation of Southern California" in the credits.

You can learn more about Far East Deep South and how to screen the film at [www.FarEastDeepSouth.com](http://www.FarEastDeepSouth.com) as well as follow us on Facebook/Instagram @FarEastDeepSouth. We look forward to theaters and events opening up live so you can all see the film in person some day. In the meantime, we wish you all a safe and healthy 2021!



*HFSC also thanks Baldwin Chiu better known as "War Machine" for his volunteer work with the Avengers Initiative at our annual emPOWERment Forum!*



## SUPPORT LOCAL!

IN AN EFFORT TO SUPPORT OUR LOCAL BLEEDING DISORDERS COMMUNITY DURING THE PANDEMIC, WE ASKED OUR FAMILIES TO SUBMIT ADS FOR THEIR LOCALLY OWNED BUSINESSES!

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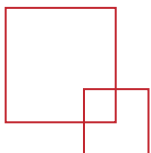
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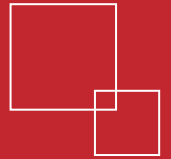


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IN ALLIANCE WITH  UCLA Health

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# VACCINATION INFORMATION



NHF recognizes that individuals with bleeding disorders may have questions and concerns relevant to the new COVID-19 vaccines, including any implications specific to their conditions. The following FAQs are therefore meant to address some of the most common questions. Please note that these answers were created for broad purposes and that affected individuals should engage closely with their healthcare provider to discuss the possibilities of vaccination, including potential contraindications (if any), and specific questions related to safety and efficacy. Given the nature of this virus, rapid developments in vaccines, and the upcoming transition in our federal government, this continues to be a very fluid situation.

Two mRNA COVID-19 vaccines – from Pfizer-BioNTech and Moderna – have already been approved and are currently being administered to people in the US and internationally. There are several other vaccines that are in development and will be considered for “Emergency Use Authorization” (EUA) from the U.S. Food and Drug Administration (FDA), including two viral vector vaccines – developed by Oxford-Astrazeneca and Johnson & Johnson.\* These additional vaccines are currently in large, phase III clinical trials and yielding promising results thus far. NHF will keep the bleeding disorders community updated as new information becomes available.

## **What is an “Emergency Use Authorization” (EUA)?**

An Emergency Use Authorization (EUA) is a mechanism to facilitate the availability and use of medical countermeasures, including vaccines, during public health emergencies, such as the current COVID-19 pandemic. Under an EUA, FDA may allow the use of unapproved medical products in an emergency to diagnose, treat, or prevent serious or life-threatening diseases or conditions such as infection with the virus that causes COVID-19 disease when certain statutory criteria have been met, including that there are no adequate, approved, and available alternatives.

## **These vaccines were developed very fast. Are they safe?**

It is true that the Pfizer/BioNTech and Moderna vaccines have been developed very quickly. But the technology behind the vaccines is not new. They both are what are called mRNA vaccines, which function very differently than the types of vaccines used in the past. mRNA vaccines, rather than using a weak or ineffective sample of the virus to trigger antibodies – like in a flu shot – mRNA vaccines instruct your cells to create a harmless protein (called “spike” protein) that your body recognizes as foreign, creating an immune system response. Scientific papers describing this mRNA technology, discovered by Hungarian scientist Katalin Karikó (who oversees mRNA work for BioNTech) were first published in 2005.

## **Is it safe for a person with a bleeding disorder to receive the COVID vaccine?**

If you have a bleeding disorder, there are no contraindications to being vaccinated with either vaccine now available via EUA status for intramuscular administration. It should be noted that, immune tolerance therapy, treatment for hepatitis C, and HIV and other conditions including the use of immunosuppressive agents do not preclude a person from receiving either available vaccines. For patients in a clinical study, vaccination should be reported to the study investigators

## **Would I be in a priority group to receive the vaccine with a bleeding disorder?**

Since people with bleeding disorders are not at a greater risk of contracting COVID-19 or developing a severe form of the disease, they are not considered a priority group. General selection rules will apply for those with a bleeding disorder. Bleeding disorder patients in the risk groups identified by age, state of health, health care or other essential worker will be vaccinated as a priority like others in the general population with the same risks. Priority groups will vary by state.

## **Is there a particular type of vaccine I should choose?**

Currently there is no reason to choose a particular type of vaccine. If you are considering enrolling in a gene therapy clinical trial, you should avoid any vaccines that use a modified adeno-associated virus (AAV) since these viruses are used in gene therapy. No vaccinations currently approved or in development are using AAV viruses. However, vaccines that are using a different virus, adenovirus, are being tested and are unrelated to AAV therefore would not be a problem with enrolling in a gene therapy clinical trial in the future.

## **Will I have a bleed if I take the vaccination?**

The vaccination is administered intra-muscularly but the smallest gauge needle needs should be used (25-27 gauge), if possible. Some vaccines must be administered using the accompanying needle-syringe combination, and so the use of an alternative needle may not be possible or desirable.

It would be preferable for you to infuse with a factor replacement product prior to or right after the vaccination and applying pressure for 10 minutes after the vaccination. Patients receiving emicizumab may be vaccinated by intra-muscular injection at any time without receiving an additional dose of FVIII. Patients with von Willebrand Disease or rare bleeding disorders should consult with their hematologist regarding special precautions prior to receiving the vaccination. All rare bleeding disorder patients (including those with thrombocytopenia and/or platelet function disorders) should be vaccinated. Patients on anticoagulants should have prothrombin time testing performed within 72 hours prior to injection to determine international normalized ratio (INR); if results are stable and within the therapeutic range, they can be vaccinated intramuscularly.

Following the vaccination, the area should be monitored for hematoma formation immediately for 10 minutes to reduce bleeding and swelling and by self-inspection 2-4 hours later at home to ensure that there is no delayed hematoma. Discomfort at the injection site is to be expected. Discomfort in the arm felt for 1-2 days after injection should not be alarming unless it worsens and is accompanied by swelling.

Any adverse events should be reported to the physician and any allergic reactions need to be reported immediately to your physician or you need to go to the emergency room. To read more about vaccinations in general please click on this link for NHF’s Medical and Scientific Advisory Council’s recommendations, MASAC Document 221 – Recommendations on Administration of Vaccines to Individuals with Bleeding Disorders.

## **Should I take the vaccination if I am pregnant or breastfeeding?**

Currently, there is limited data on the safety of COVID-19 vaccines for women who are pregnant or breastfeeding, although studies are planned. The Centers for Disease Control and Prevention (CDC) and the FDA have safety monitoring systems in place to capture information about vaccination during pregnancy and will closely monitor reports. Individuals who are pregnant and considering vaccination for COVID-19 are encouraged to speak with their clinicians. According to the CDC, key considerations that should inform these conversations include likely exposure to the virus that causes COVID-19; risks of COVID-19 to the pregnant patients and their fetus; and current knowledge about available vaccines including efficacy, known side effects, and the lack of available data in this population.

\*Since publication the single dose Johnson and Johnson vaccination has been approved for emergency use for those 18 and older.

## UPCOMING EVENTS



### **SOCAL EMPOWERMENT FORUM AND WORLD HEMOPHILIA DAY**

*Saturday, April 17  
8:30am-12:30pm  
CVENT*

*Celebrate World Hemophilia Day and Learn to be a Stronger Advocate!*

*Keynote Speaker: Len Valentino, MD, President & CEO, NHF  
Special Visit from Mexico and Nigeria Hemophilia Foundations!*

*Grab your best Red outfit for our Light It Up Red Fashion Show, and play our Booth Trivia Game for a chance to win prizes!*

*8:30-10:00am: Booths Open- Play Our Booth Trivia Game!  
10:00am-12:30pm: Program*

**Register: <https://cvent.me/A3gOBR>**

*Each household will receive a \$50 Walmart gift card after attending the event.*

 Hemophilia Foundation  
of Southern California

### **Virtual Family Information Day**

**Saturday, May 22, 2021  
8:30 a.m.- 12:45 p.m.**

**CVENT**

Register:

**<https://cvent.me/348BmY>**



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¡Si desea una copia de este boletín de noticias en español, por favor póngase en contacto con la oficina de HFSC al 626-765-6656 o [info@hemosocal.org](mailto:info@hemosocal.org)!

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