

Infusions

HFNC Welcomes Marc Pangilinan *We're so glad you're here!*



THIS IS MARC, OUR NEW EXECUTIVE DIRECTOR!

I am incredibly honored to be able to introduce myself as the new Executive Director of the Hemophilia Foundation of Northern California. I'm eager to continue the great work of this organization by enhancing the quality of life for all those in our community by providing support, education, outreach, and advocacy.

So who am I? Let's just get this out of the way: I am a fairly new transplant to Northern California. I relocated from New York this past July to join my girlfriend Jess who has been based out of the East Bay for a few years now. I only say that so hopefully you'll forgive my sometimes-utter cluelessness about some of the more obvious aspects of West Coast living!

One thing I can assure you though is that I am no stranger when it comes to bleeding disorders. First and foremost, I am a patient with Severe Hemophilia A. I was diagnosed at birth back in the late 80s and to this day still actively work to learn how to better manage it as best I can alongside

the other aspects of life. From a professional standpoint, my previous roles include being the Programs and Events Manager for the New York City Hemophilia Chapter and then as the Hemophilia Community Liaison (Northeast Region) for Novo Nordisk.

You may have heard the term "changing landscape" recently within the world of bleeding disorders. Simply put, this refers to the significant advancements in the medicines within a relatively short period of time. There is no denying that bleeding disorders, particularly Hemophilia, in some respects has become significantly more manageable over the past years due to these advancements.

While that may be true for some in the "traditional" hemophilia patient population, there are still challenges and unmet issues that exist and continue to grow even if they aren't as apparent as a bleed, nor do they seem that they can be solved by something as simple as a dose of treatment.

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ALTUVIIIIO™
Antihemophilic Factor (Recombinant),
Fc-VWF-XTEN Fusion Protein-ehtI

SWITCH IT UP with ALTUVIIIIO™

Sanofi Community Relations and Education (CoRe) Managers are dedicated professionals who can provide personalized education about ALTUVIIIIO, and point you toward helpful support and resources.



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YOUR CoRE TODAY



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Serving NorCal

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These are what I like to call “evolving needs”.

You might have even experienced some of them yourself:

-  ***The rise of mental health illness diagnoses among those with bleeding disorders***
-  ***Navigating the complexities of health insurance to attain consistent healthcare treatment***
-  ***Moderate to extensive joint damage occurring later in life which impacts quality of life and life decisions***
-  ***The unequal level of care, attention, and education***
-  ***Inequitable levels of access to treatment experienced by various underrepresented populations***
-  ***Inconsistent care outside of HTCs***
-  ***The physical and psychological consequences of late and/ or misdiagnoses of mild/moderate hemophilia and other rare bleeding disorders (VWD, F7, GT, etc)***

The list goes on. As Executive Director, my main focus is to determine what are the evolving needs that are specific to the Northern California bleeding disorders community and figure out novel ways to solve them.

I’m excited to work alongside the rest of the HFNC team: our committed Board of Directors, our part-time contractors, and especially our Associate Director, Ashley Gregory, whose steadfast dedication over the years to improving the lives of those in the HFNC community (and beyond) has been nothing short of awe-inspiring and sets a high standard to be upheld. Additionally, I look forward to working with our other valued stakeholders such as our HTCs and local representatives from our pharmaceutical manufacturer and specialty pharmacy partners along this journey.

This is where HFNC needs your help. I greatly encourage you to speak up and share your thoughts as that is the only way for us to really know where the pain points exist.

I look forward to meeting you all at one of our many upcoming events (be sure to keep an eye out for our e-mail & social media invites so you register ASAP to reserve your spot!).

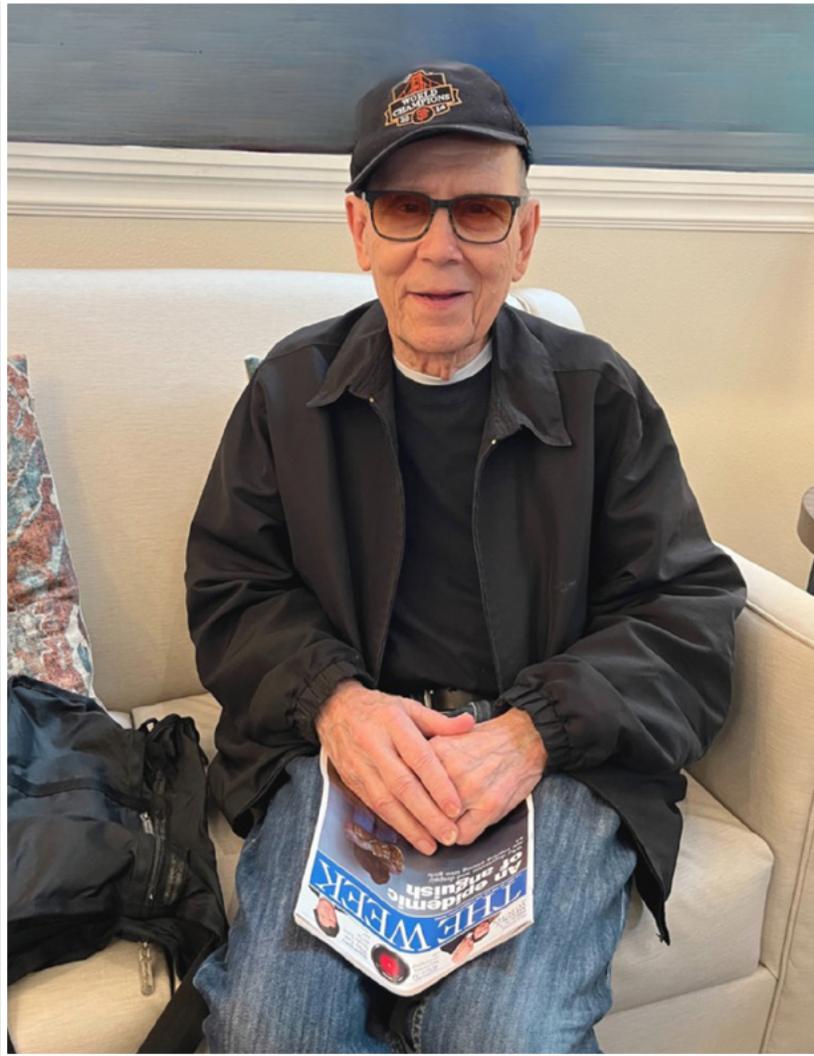
See you soon - **Marc Pangilinan** 



HAVE ANY QUESTIONS, I WANT TO HEAR FROM YOU

MARC.PANGILINAN@HEMOFOUNDATION.ORG

Wilbur Curtis



Founding member of Hemophilia Council of California and Central California Hemophilia Foundation

Wilbur Curtis passed away on February 19th; he was 94 years old. He lived in West Sacramento from the time he was 12 until he moved into assisted living with his wife Gloria in 2017. He was a schoolteacher for over 30 years, primarily in the Washington Unified School District. He founded the Central California Hemophilia Foundation in 1969 and was instrumental in the creation of the Hemophilia Council of California. He was a great teacher, a wonderful father, and a proud member of the bleeding disorders community. A memorial service will be held on Saturday, May 18th in Sacramento; details are available at the link below. Open service 10AM-2PM, [Naumann and Son](#), Sacramento.

<https://www.legacy.com/us/obituaries/name/wilbur-curtis-obituary?id=54548114>

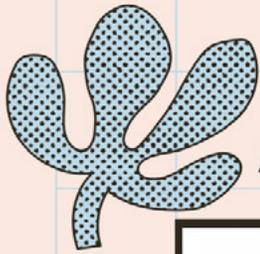
We are grateful to Wilbur Curtis for his contributions to our community and recognize the loss of a pioneer. Condolences to his son Randall Curtis, President, HFNC Board of Directors, a family legacy to be proud of for sure. Donations in Wilbur Curtis' honor may be made to Wilbur and Gloria Curtis Scholarship Fund at [Central California Bleeding Disorders Foundation](#). 🔥

HFNC Names New Medical Director DR. Tiffany Lucas, Kaiser



Hello HFNC! I am a pediatric hematologist/oncologist with a focus in bleeding disorders care and am so glad to support HFNC. My training in pediatrics was at Children’s Hospital of Philadelphia followed by pediatric hematology/oncology training at University of California San Francisco. I went on to do a one year fellowship in bleeding disorders funded by the Hemophilia Thrombosis Research Society Clinical Fellowship Award. I have enjoyed getting to know the patients and families that are in our bleeding disorders community as one of the Camp Hemotion physicians in years past. Currently, I am a pediatric hematologist/oncologist working at Kaiser Oakland.

HFNC welcomes Dr. Lucas to our team and want you as a community member to know that if you have questions or concerns you can email ashley.gregory@hemofoundation.org or text/call 510-658-3324 or [submit via website](#) here and we will consult with Dr. Lucas to provide a response. 🔥



Meet the Wonderful

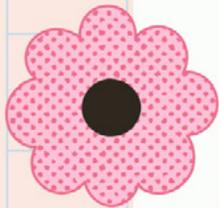


Ms Gregory



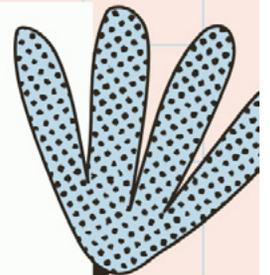
Introduction

My name is Ashley Gregory, I am excited to announce my promotion at HFNC to Associate Director.



All About me

Ashley Gregory is a woman with a bleeding disorder and parent of children with bleeding disorders. She has been involved in the community since 2014, continuously attending national and local events to meet stakeholders, gather information and develop relevant programming and advocacy. She volunteered for many events and projects for which she was awarded volunteer of the year for two years (2015, 2016) and was officially hired by HFNC in spring 2019. Currently, she volunteers as Director of FAIR Time for Women and as Vice President of the Board of Danny's Dose. Ashley wants to get to know you, your family and your needs and encourages you to let her know what is on your mind. In her spare time, Ashley can be found in her seaside town creating culinary delights, walking by the ocean, listening to podcasts, watching sunsets and enjoying her adult children and pets.



THIS MONTH:
54
new community
members welcomed



The
Hemophilia
Foundation of
Northern California

FOR ALL BLEEDING DISORDERS

Unite
for Bleeding Disorders

THIS YEAR:
106 new community members welcomed
47 welcome kits sent
33 American Medical IDs ordered



Start Your Walk Team
Save the Date
Sunday, November 3, 2024
Heather Farm Park
Walnut Creek



510-658-3324

<https://www.hemofoundation.org/support/fundraisers/unite-for-bleeding-disorders.html>

Participate in Research



About CVR

Your voice is at the center of NBDF's CVR. This community-powered registry will help researchers understand what it really means to live with a bleeding disorder and how current treatments, therapies, and policies affect the community. CVR will collect information from the people directly affected: people with bleeding disorders, their parents, siblings, partners, and caregivers.

People who participate in CVR will share information consistently over several years through surveys. This will allow researchers to better understand how bleeding disorders affect individuals and their family members across their lifespan. It will also help participants understand their individual situation and how a bleeding disorder affects their life.

The confidential, de-identified aggregate data gathered through CVR will ultimately contribute to the goal of improving clinical outcomes and quality of life and identifying research questions important to the community. 🔥



NATIONAL
BLEEDING DISORDERS
FOUNDATION
Formerly NHF

Enroll Now



THE FEMALE FACTOR
affected and connected

Save the Date

February 6-9, 2025

We added an extra day!

"This was my most favorite retreat that I've ever been to. The speakers were great, topics were wonderful, the breakout session options were awesome"

"I liked all the speakers"

"The schedule was great and the speakers were fantastic. I enjoyed everything. It was the best retreat so far"

"I was really happy we were next to the beach"

[Contact your Congressman](#); ask them to pass Safe Step Act (H.R. 2279)

Reform Step Therapy Practices

Step therapy, sometimes known as “fail first,” is a practice employed by many insurers that requires patients to try lower-cost therapies before being approved for the treatment that their doctor prescribed – even when doctors are certain that the cheaper option won’t be effective.

When inappropriately used, step therapy undermines the clinical judgment of health care providers and puts patients’ health at unnecessary risk.

Many patients must try multiple drugs before finding one that works for them, so the ability to remain on a drug that works is critical. A survey of more than 1,400 patients conducted in 2016 by the Arthritis Foundation revealed:

-  Over 50% of all patients reported having to try two or more different drugs prior to getting the one their doctor had initially prescribed.
-  Step therapy was stopped in 39% of cases because the drugs were ineffective, and 20% of the time due to worsening conditions.
-  Nearly 25% of patients who switched insurance providers were required to repeat step therapy with their new carrier.
-  A majority of respondents experienced negative health effects from delays in getting on the right treatment.

Step therapy should not disrupt a patient’s ongoing care or destabilize treatment if they change jobs or insurance carriers. People with arthritis depend on life-changing medications to prevent further progression of the disease and joint degradation. Step therapy requirements can be less administratively burdensome to patients and providers if exceptions are provided in cases where:

1. The treatment prescribed is contraindicated or has been ineffective in treating a patient’s disease;
2. The treatment under a step therapy protocol is reasonably expected to be ineffective;
3. The treatment may cause an adverse reaction or physical harm to the patient;
4. The treatment is not in the best interest of the patient or could interfere with the patient’s ability to complete activities of daily living; and
5. The patient is stable for his or her disease on medications already selected by a provider.

What Congress can do.

Congress can pass the Safe Step Act (H.R. 2279). This bipartisan legislation was first introduced in the 115th Congress by Representatives Brad Wenstrup, DPM (R-OH) and Raul Ruiz, MD (D-CA) who have both encountered step therapy in their own practice of medicine.

The legislation streamlines step therapy for patients with employer-sponsored insurance by establishing a clear exceptions process for step therapy review by health insurance plans; establishing a reasonable and clear timeframe for override decisions; and requiring insurers to consider the patient’s medical history, the provider’s expertise in partnership with their own patient, and respect for the health care provider’s professional judgment – before a health plan can delay or outright deny a patient’s ability to access a medically necessary treatment. (www.arthritis.org/accessed04/08/2024) 

[Step Therapy Federal Map](#)

Family Camp 2024



Save the Date

March 7-9, 2025

Tattooed Bleeder

By Pamela Lauer



I get funny looks when I tell people I have hemophilia. The cynical looks may be because I am a woman. It may be because I have so many tattoos. I actually have (if you count ones I have covered with others) 15 tattoos, I think. My favorite one is always my most recent one but this time I really mean it.

My newest tattoo doubles as a target for me. I use the eye of the moth as a bull's eye to set my vein. Before this tattoo I had never successfully infused my inner right arm (elbow pit if you know what I mean). I have been able to infuse a good four out of six times I have had to infuse as of late. Welp, nothing and no one is perfect!

hand last week when I was in the hos-

to incorporate those veins in another "target" for my left hand. I have also invited my husband to consider getting a matching tattoo on his hand since it is the hand where our wedding tattoos are placed on our ring fingers.

I will likely get more tattoos. I even took a picture of the veins of my left

Some people ask, "Did you get all those tattoos before you were diagnosed a bleeder?" "Nope." "Do you infuse before you get a tattoo?" "Nope."

Firstly, as a mild, my bleeds are usually slow trickles that start out as a painful swelling and increase to an overwhelming throbbing ache as I ignore it...or treat it (as I should do immediately). Not often do I get a nose bleed or a gushing open wound. More importantly, when it comes to the matter of tattoos, a good tattoo artist giving a tattoo that takes only a couple hours (think something the size of a soft ball or smaller), should not even make you bleed. A huge full sleeve or back piece, something that takes hours of sitting, possibly more than one sitting, now that, I would infuse for. Any bleeder should infuse for something large and invasive like that. As a mild, I can get away with not always infusing. I would, however, highly encourage anyone who is moderate or severe to infuse before a tattoo...after all, having 100% factor levels can't hurt. Tattoos, those hurt.

Let's be honest, tattoos are harmful to your body. It is repeated trauma to the skin and also introduces foreign materials under the skin. It's important to be well hydrated and fed before a tattoo. It's important to know it will hurt and to know that afterward you may feel a bit light headed or even have a loss of appetite for a while. Your body is surviving a repeated needle attack. Getting a tattoo, it's not like infusing, but it still hurts. That is why I usually invite at least one friend to accompany me.

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I invite someone that knows I have hemophilia (all my friends know that) to come distract me when I get a tattoo. Mostly it's just to keep my mind off and have someone to chat with. I am also sure to invite someone who is a good advocate and can watch me, if I am turning green they can say, "Hey she needs a break." It is not uncommon for folks to get so light headed they pass out from getting a tattoo (again, eat before you get a tattoo!). I haven't passed out since the first one but, I have asked for breaks to drink fluids and stretch. Tattoos are hard work for the artist and the canvas (the tattoo receiver).

The sound of the needle can even cause some trauma, especially in folks who have had a bad tattoo experience in the past. It is, of course, always ok to stop the work if you aren't feeling well. Don't forget though, once you start, that ink is in there and that image or partial image will be on your skin pretty much, forever. You do have to have some mental strength to ignore the pain, but it does eventually go numb-ish. Ask the tattoo artist if you can listen to music, some places have a screen so you can watch a film. I like to bring something to hold too. I often bring a stone or a stress ball just to have something else to think about.

It's always nice to find a good artist and stick with them if you like their work, and if you know they don't have a "heavy hand". Again, a seasoned artist shouldn't cause a lot of bleeding. Let's face it though, Bleeding and scarring are real possibilities with any tattoo and home tattoos or "stick and pokes" (where a needle without a proper tattoo gun and some black ink are tapped into the skin) should be avoided...this is a forever artistic reminder to the whole world, take the time to do it right. (I am not talking about tattoos done by professionals who use old methods with needle and ink, I am talking about your drunk buddy having a great idea...) Spend money on a tattoo, it's permanent and it is self respect, you know? If you do your homework and find an artist whose style you like, who has good reviews and who has years of experience at a clean and safe shop, a bleeder can get ink. It's totally possible. It almost just makes sense, you know? We get poked all the time, what's a few more sticks for something meaningful?

I have moved a lot and have had many artists do my tattoos. This means I have had a lot of experiences with different people's skills. Newbies, they will make you bleed, they push down too hard. If you are a bleeder, choose a seasoned professional, for sure! I have a couple tattoos I let someone give me with a gun they got off the internet or with a needle and India ink, like mentioned above. One of my "home" tattoos was giant, painful, bloody and full of "holidays".

A holiday is what the professionals call a part of a tattoo where an artist held the gun in the same spot so long it made a permanent scar of bubbled up skin with thick black ink welled up in the wound. They are scars and bumps that, even when covered with a new tattoo, will not go away. I once let a man I was dating put a huge tattoo on my left arm. It had a few large holidays in it and the piece I covered it with a couple years later so I could stop thinking of that guy every time I saw my own arm, it cost me \$1,600 and six hours of seat time. A free tattoo is never free!

Then why get a tattoo? For many, tattoos are a sign of strength. My tattoo images have personal meaning to me. My tattoos are all nature related and they serve as guidance and protection for me. Some people get tattoos as a part of their cultural heritage. Some people get tattoos to express something they don't want to say out loud. That is why they are popular with bikers and gangs. A tattoo can say, "Look how tough I am!" (Tattoos on elbows, ribs and hands say that for sure, boney spots hurt the most!) A tattoo can also easily say, "Look how ignorant I was when I was young!" so, be careful that you only tattoo something onto your skin if you mean to express that feeling, image or emotion forever...for-e-ver. I don't recommend getting a tattoo of a word in a foreign language, especially if you don't know for sure what the image means.

There is an urban legend of a woman who wanted Chinese symbols for tattoos that mean "peace and love" but she got images that actually read, "pencil case". I can't prove that story is true. I can say it's a good warning for anyone considering new ink. Again, it is much easier to get a tattoo than remove it. It's also more painful to remove it!

I have a friend who got tattoo laser removal surgery. She said it was ten times more painful than getting the tattoo! The removal had to be done three times in three separate sittings and you can totally still see the whole tattoo. Now it's just a scar without ink in it...but it's painfully obvious what that tattoo was, and it's been gone for at least five years.

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Tattoos and even piercings are not something to get on a whim. There are health obligations. Caring for a tattoo in the first few days afterward are dire to how the art turns out in the end. When I had my marriage tattoo done on my finger (fingers are very painful and have to be done over and over to ensure the ink stays as you sluff skin off your hands frequently due to washing and using them) I decided to can tomatoes from the garden two days after the second time I had it worked on. Most of the ink came out from being plunged into the highly acidic juice from the tomatoes. All that pain and hard work for nothing!

To properly care for a new tattoo you have to start before you even get the tattoo. Be sure that if the body part you are tattooing is usually covered by clothes that you are going to wear to the appointment that you don't mind getting ink on that may not come out. It's best not to wear clothes over that site for at least the rest of the first day. It is going to be sore, think about a skinned knee or road rash, it's kind of like that. Think about what you are going to do in the next month. Plan to go swimming in a pool or river? Don't get that ink now! Plan to garden a lot, don't get a tattoo on your hand just before gardening season. Planning a trip to a beach to walk barefoot...don't get a tattoo on your foot weeks before the trip...do it months before. Careful planning is dire to a tattoo that heals right and looks good.

A new tattoo feels like an open wound. That is actually what a new tattoo is. That means you have to treat it like a wound. I recommend transparent dressing if you can get it. They sell this magical saran wrap for the skin at pharmacies. It's a clear coating of plastic that sticks to the skin and seals out bacteria so the wound can heal. This stuff is awesome. Just put it on the tattoo right after it's finished and cleaned up and leave it on for about five days. You can shower, you can slap (NEVER SCRATCH!) the tattoo as its healing to alleviate the itch and you can still see the new image to show off to others!

If you don't use that, maybe you don't want plastic on your wound, which I totally get. If you don't use that, you must, I mean MUST keep the tattoo moist with ointment so the ink does not flake out of the wound. I think it's okay to use skin healing creams for the most part. Again, never scratch a new tattoo. Oh, and if you choose to add ointment, know that the ink will continue to leave stains on your clothes and sheets! I don't use any ointment with petroleum in it. I used to use petroleum jelly when I got tattoos. I noticed that the skin doesn't like the petroleum and will "spit it out" of the wound site along with ink, making the new tattoo lighter and/or have missing spots where ink didn't stay.

Point is, learning to stab yourself with a needle when you are already in pain takes practice, and sometimes it takes a permanent target. Learning to self infuse has been a real challenge for me. My newest tattoo has helped me place a vein and get more confident, even if I don't get it every time. I know I am grateful for the ink in my skin pointing the way toward self preservation! Since getting this tattoo I can now sometimes infuse before a hike or beach walk and totally avoid the pain all together. I have a new confidence in my outdoor activity and that is leading to weight loss too. Never let someone tell you tattoos aren't good for you, it's just a matter of how you use them! :)🔥

WHERE YOU CAN FIND US



LinkedIn: [hemophilia-foundation-of-northern-california](https://www.linkedin.com/company/hemophilia-foundation-of-northern-california)



Youtube: [HFNC1958](https://www.youtube.com/channel/UC1958)



Twitter: [HemoFoundation](https://twitter.com/HemoFoundation)



Facebook: [HemoFoundation](https://www.facebook.com/HemoFoundation)



Instagram: [@hemo_norcal](https://www.instagram.com/hemo_norcal)



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REGISTRATION IS OPEN!



GREAT AMERICA
SANTA CLARA, CA

Read more at www.hemofoundation.org/events >

LIMITED TO 200 ATTENDEES

Infusions Production Team



It takes a lot to produce issues of INFUSIONS.

The team is looking for more contributors!

Would you like to join?

This is the last edition that Pamela Lauer will be contributing to as part of the INFUSIONS team.

We want to thank her for her contribution!

If you are interested in joining the team, please email

ashley.gregory@hemofoundation.org

TEE OFF IN STYLE

UNITING MEN LIVING WITH BLEEDING DISORDERS



TOP GOLF

MUST BE REGISTERED TO ATTEND
Ages 18+

HFNC Men's Meetup

Treat yourself to our exclusive presentation on **Gene Therapy**, two full hours of play, and enjoy a delicious meal. All **Free Of Charge**.



Including Mosi Williams UCSF
HTC Facilitator



TOP GOLF

10 Topgolf Drive
San Jose, CA 95002



Scan Here

Limited Spots Available
RESERVE YOUR SPOT TODAY!

Contact: Ashley Gregory - (510)-658-3324
ashley.gregory@hemofoundation.org - hemofoundation.org/events



Kid's Page



Spring Crossword Puzzle

Across

5. A spectrum of color in the sky when it rains.
7. A colorful plant with leaves and petals.
8. A circular device that keeps the rain off your head.
11. The month in which we celebrate moms.
12. A winged insect that comes in many colors.

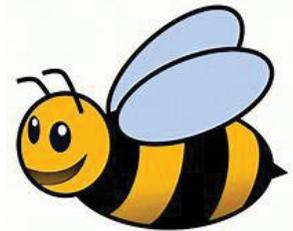
Down

1. One of the earliest birds to appear in spring.
2. _____ showers bring May flowers.
3. A sport played with a bat and ball.
4. The early bird gets the _____.
6. The month in which spring starts.
9. When snow and ice turn into water.
10. The color of grass once it comes back to life.

1. What do you call a well-dressed lion?
2. Why are frogs so happy?
3. What did the deciduous tree say to spring?
4. Why couldn't the sunflower ride its bike?
5. When do orangutans fall from the sky?
6. Why did the worm cross the ruler?
7. Why did the bee's hair smell sweet?
8. Why are flowers so popular?
9. Why did the baby chick cross the road?

● Answers: 1. A dandy lion 2. They eat whatever bugs them. 3. What a re-leaf. 4. It lost its petals. 5. During Ape-ril showers! 6. To become an inchworm. 7. Because it used a honeycomb. 8. They have a lot of buds. 9. To meet up with her Peeps.

<https://www.countryliving.com/life/entertainment/a43348631/best-spring-jokes/#spring-jokes-for-kids>



Haikus

A Haiku is a type of short form poetry that originated in Japan. Traditional Japanese haiku consist of three phrases composed of 17 phonetic units in a 5, 7, 5 pattern. Here are two, can you write a Haiku too? Wikipedia

Haiku's are easy

But some don't make sense

Refrigerator



If puddles could talk

I think that they would tell me
to splash my sister



CAMP

HEMOTION

2024

**REGISTRATION
IS OPEN!**

23-29

June

**Camp Oakhurst,
Coarsegold, CA 93614**

**Campers 7-14
Junior Counselors 15-17
Assistant Counselors 18-20
Adult Counselors 21+**

Register hemofoundation.org/CampHemotion



Make yourself able to cope in the event of an emergency



FEMA

Environmental emergencies disproportionately impact people with disabilities. During an evacuation, they are more likely to be left behind or abandoned due to insufficient planning, inaccessible transportation, or shelter which lacks the necessary accommodations. www.fema.gov, April 8, 2024

[Click here](#) to access a video of Sherman Gillums at the Federal Emergency Management Agency, who offers guidance for people with disabilities.

People with disabilities can get listed with their State Office On Emergency Management; [Click Here](#)

CALENDAR

MAY

5/5/24	SpringFest/Family Education Event	Great America, Santa Clara, CA
5/11/24	Board Meeting	In person, San Francisco, CA
5/27/24	Memorial Day	Holiday HFNC closed

JUNE

6/2/24	Men's Meetup	Dave & Buster's Milpitas
6/11/24	Board Meeting	Virtual
6/23/24-6/29/24	Camp Hemotion	Camp Oakhurst, Coarsegold CA

JULY

7/4/24	Independence Day	Holiday HFNC closed
7/9/24	Board Meeting	Virtual
7/29/24-8/2/24	Strategic Planning/HFNC closed	In person

AUGUST

8/13/24	Board Meeting	Virtual
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SEPTEMBER

9/2/24	Labor Day	Holiday HFNC closed
9/6/24-9/8/24	Familia de Sangre	Anaheim
9/10/24	Board Meeting	Virtual
9/11/24-9/14/24	NBDF	Atlanta, GA

OCTOBER

TBD	CSL Behring's Gettin' in the Game	TBD
10/8/24	Board Meeting	Virtual

NOVEMBER

11/3/24	Unite for Bleeding Disorders Walk	Heather Farm Park, Walnut Creek, CA
11/12/24	Board Meeting	Virtual
11/18/24-11/21/24	NBDF Chapter Leadership	TBD
11/23/24-11/24/24	Thanksgiving Holiday	Holiday HFNC closed

DECEMBER

12/1/24	World AIDS Day	AIDS Memorial Golden Gate Park San Francisco, CA
12/3/24	Giving Tuesday	Campaign
12/7/24	WinterFest	East Bay
12/14/24	WinterFest	Fresno
12/24/24	Christmas Eve	Holiday HFNC closed
12/25/24	Christmas Day	Holiday HFNC closed
12/23/24-1/2/25	HFNC Office Closed	Holiday HFNC closed

JANUARY 2025

1/1/25	New Year's Day	Holiday HFNC closed
1/2/25	HFNC reopens	Virtual

HFNC Hemophilia Foundation of Northern California
<https://www.hemofoundation.org/>

AFFILIATED ORGANIZATIONS

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

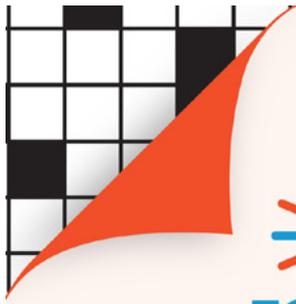
HFA Hemophilia Federation of America
<http://www.hemophiliafed.org/>

NBDF National Bleeding Disorders Foundation
<https://www.hemophilia.org/>
NBDF Chapters (See full list at NBDF)

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

HEMOPHILIA TREATMENT CENTERS HTC's

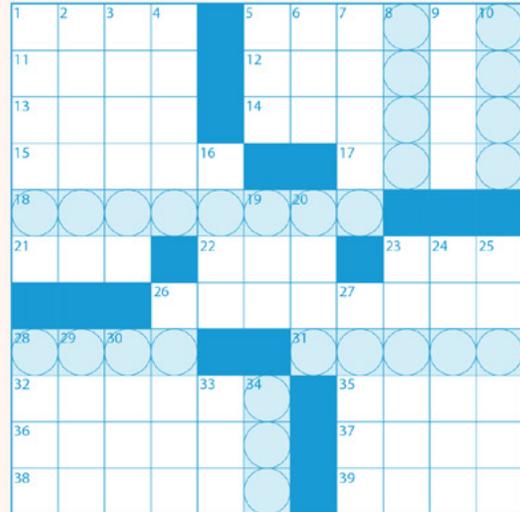
Stanford University Medical Center
<https://www.stanfordchildrens.org/en/service/hematology>
 UCSF Benioff Children's Hospital Oakland
<https://www.childrenshospitaloakland.org>
 University of California at Davis
<https://www.ucdmc.ucdavis.edu/hemophilia/>
 University of California San Francisco
https://www.ucsfhealth.org/clinics/hemophiliatreatment_center/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



CAN YOU SOLVE

**FOR A DIFFERENT
HEMOPHILIA A
TREATMENT?**

Test your HEMLIBRA knowledge



ACROSS

- 1. Wine barrel
- 5. Deep fissures
- 11. Mideast gulf port
- 12. District
- 13. Ripped
- 14. Familiar with
- 15. Mean
- 17. Roost
- 18. The #1 prescribed prophylaxis for people with hemophilia A without factor VIII inhibitors*

*According to IQVIA claims data (various insurance plan types) from September 2021–August 2022 (refreshed November 2022), accounting for prophylaxis use in the US.

- 21. Calendar divs.
- 22. Regret
- 23. Banquet hosts (abbr.)
- 26. International travel necessity
- 28. Check out the ____ treated bleeds data with HEMLIBRA
- 31. Number of dosing options HEMLIBRA offers

- 32. Small hole in lace cloth
- 35. Central Plains tribe
- 36. Melodic
- 37. Towering
- 38. Reduce
- 39. Spanish cheers

DOWN

- 1. Memorable, as an earworm
- 2. Devotee
- 3. Medical fluids
- 4. Prepare to propose, perhaps
- 5. PC's "brain"
- 6. Owns
- 7. Concert venue
- 8. See Medication Guide or talk to your doctor about potential ____ effects
- 9. Winter hrs. in Denver and El Paso
- 10. HEMLIBRA is the only prophylactic treatment offered this way under the skin

- 16. Pre-Euro currency in Italy
- 19. Subway alternative
- 20. Relax
- 23. Human
- 24. New Orleans cuisine
- 25. Mentally prepares
- 26. Collared shirts
- 27. Instagram post
- 28. Ardent enthusiasm
- 29. Brontë heroine Jane
- 30. Old Portuguese coins
- 33. Opposite of WNW
- 34. More than ____ thousand patients have been treated with HEMLIBRA worldwide[†]

[†] Number of people with hemophilia A treated as of October 2021.

SOLUTIONS

ACROSS: 1. cask, 5. chiasm, 11. Aden, 12. parish, 13. tore, 14. used to, 15. cruel, 17. nest, 18. HEMLIBRA, 21. yrs, 22. rug, 23. M.C.s, 25. pasport, 26. zero, 31. throo, 32. eyelot, 35. Dicoe, 36. anose, 37. ear, 38. lessen, 39. oles
DOWN: 1. canny, 2. adove, 3. serms, 4. knool, 5. CPl, 6. has, 7. arena, 8. side, 9. MSts, 10. shot, 16. lra, 19. bus, 20. rest, 23. morral, 24. Creole, 25. steis, 26. pokos, 27. photo, 28. zeal, 29. Eye, 30. Res, 33. ESt, 34. ten

Discover more at HEMLIBRA.com/answers

INDICATION & IMPORTANT SAFETY INFORMATION

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**.



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.

Your body may make antibodies against HEMLIBRA, which may stop HEMLIBRA from working properly. Contact your healthcare provider immediately if you notice that HEMLIBRA has stopped working for you (eg, increase in bleeds).

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

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For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
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Revised: 03/2023



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The National Bleeding Disorders Foundation



Left to Right: Lynne Kinst, Executive Director, Hemophilia Council of California, Constituent and Child, Staffer, Randall Curtis, President of Board of Directors, Hemophilia Foundation of Northern California and Dawn Pollard, Vice President of Board of Directors, Hemophilia Foundation of Northern California

The National Bleeding Disorders Foundation (AKA NHF) held its annual advocacy day on March 7, this year. It had been several years since I last attended Washington Days in Washington, DC. One significant difference was the weather. The last time I went it was snowing, this time the weather was beautiful. There were 428 participants representing 43 states and Puerto Rico. We were there to advocate for persons with bleeding disorders to keep their access to copay assistance programs.

Copay Accumulator Adjustor Programs (CAAPs) say copay assistance doesn't count towards out-of-pocket maximums or deductible. Only dollars paid directly by a person count. The insurance companies gladly take the copay assistance dollars and then still ask for the full deductible from the patient. Patients who can't afford the full copay amount may skip doses or go without, resulting in ER visits and permanent joint damage.

Nineteen states have passed laws prohibiting this practice, this includes "red" states and "blue" states. Federal legislation is needed to make sure that all types of private insurance plans are covered. The HELP (Help Ensure Lower Patient) Copays Act (House Resolution 830 and Senate Resolution 1375) are both bipartisan measures that have many co-signers. Dawn Pollard and I were with the California team and we visited with staff from four congressional districts and one senator.

The other issue we discussed with them was the narrowing of formularies by certain Pharmacy Benefit Managers (PBMs). Currently the United States Pharmacopeia combines drugs for hemophilia A, B, von Willebrand's and others into one class. This allows some insurance companies to severely restrict access to medication. All we did was to ask each representative or senator to write a letter to the Department of Health and Human Services asking them to enforce current Essential Health Benefits regulations that require plans to cover drugs that treat all disease states.

We had a similar effort in Sacramento on March 18, to ban copay accumulator adjustment programs at the State level. One big difference was the contingent of Future Leaders at the event. The Future Leaders program trains young people how government actually works and teaches them how to tell their story to legislators.

My team met with staff from three Assembly members and two state senators. We asked them to co-sign bill AB 2180 (Weber) to ban copay accumulators and protect patient assistance, which is awaiting a hearing in the Assembly Health Committee. The entire effort was coordinated by the amazing staff of the Hemophilia Council of California.

It was gratifying to see all of these people volunteering their time to help the bleeding disorders community and 120 other chronic diseases that will benefit from these legislative efforts. 

Randall Curtis, *President of the Board of Directors*



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