SPRING 2025

Infusions

Camp Hemotion 2025 Registration is Open

Created for the benefit and growth of children with a bleeding disorder, siblings, and children of adults with bleeding disorders. Kids will spend a week participating in campfires, games, sing alongs, and education. Scholarships are available.

To learn more, visit us at hemofoundation.org/events

IN THIS ISSUE

A NEW CHAPTER: Introducing HFNC’s New Executive Director

Dear Members and Friends of the Hemophilia Foundation of Northern California (HFNC),

It is with immense gratitude and enthusiasm that I step into the role of Executive Director of this remarkable organization. The mission of HFNC since 1958—to empower and support individuals with bleeding disorders—is one I am deeply passionate about, and I am honored to join this community as we work together to enhance the lives of those we serve.

Over the past 30 years, my career journey has spanned diverse industries, allowing me to develop expertise in financial management, membership engagement, advocacy, fundraising, and educational program development.

Although I do not personally have a bleeding disorder, I have been deeply entrenched in working with and advocating for numerous healthcare organizations throughout my career. This perspective has given me a profound appreciation for the resilience and courage of those living with chronic health conditions, and it strengthens my commitment to ensuring HFNC’s mission continues to thrive.

In my most recent roles, I led initiatives to promote physician wellness, foster equity and belonging within professional societies, and deliver impactful programs for communities in need. As the first female executive director of a 145-year-old medical society in California, I prioritized innovation, sustainability, and advocacy, and I am eager to bring the same energy and commitment to HFNC.

Beyond my professional accomplishments, my personal drive comes from a deep belief in the power of community. I have witnessed how collaborative efforts can transform lives and inspire hope, and I am committed to fostering that same spirit here at HFNC.

Looking ahead, I am excited to work closely with our dedicated board, staff, volunteers, and industry partners to build upon the strong foundation HFNC has established. Together, we will continue advocating for access to care, advancing education, and fostering a supportive network for all those affected by bleeding disorders.

About me personally: I live in Gilroy, CA. I am married with three adult sons, and two grandchildren. Although I love all animals, I’m a dog person most of all, I have two of them. I prefer the forest over the ocean. Outside of work, you will always find me hiking on the trails, identifying birds with my Merlin app that I recently discovered. Time in nature recharges me.

Thank you for welcoming me to the HFNC family. I look forward to meeting many of you in the coming months as we work together to make a lasting impact. Please reach out to me at director@hemofoundation.org to share your comments and ideas.

Sincerely, April Steger

President's Report: Randall Curtis, President of Board of Directors, HFNC

Recently, Executive Director April Steger and I attended a Chapter Leadership Seminar in San Antonio, Texas, hosted by the National Bleeding Disorders Foundation. This seminar brought together representatives from chapters across the country to share insights, best practices, and challenges in navigating the evolving landscape of services and support for the bleeding disorders community.

A key takeaway from the meeting was the varying levels of engagement chapters maintained during the pandemic. While some organizations managed to remain highly active, others faced challenges in sustaining their activities. This disparity underscores the importance of collaboration and shared learning among chapters.

One critical issue highlighted during the seminar is the need for enhanced services for underserved populations, including Latinos, individuals with non-severe bleeding disorders, and women, girls, and individuals who menstruate. These communities often face unique challenges and require tailored programming to meet their needs effectively.

In response, we are committed to expanding our offerings to address these gaps. We plan to develop new programs inspired by successful initiatives shared by our colleagues across the country. By leveraging proven strategies and fostering collaboration, we aim to strengthen our efforts in supporting these underserved groups and advancing our mission.

Randy Curtis

HEMOPHILIA FOUNDATION OF NORTHERN CALIFORNIA

SCHOLARSHIP PROGRAM

2025

- Meet Scholarship Requirements
- Individuals with bleeding disorders, as well as those impacted by such conditions, are encouraged to apply
- PORTAL IS OPEN! APPLY NOW!!

hemofoundation.org/scholarships

There is no need for you to select the scholarship that applies to your situation; the approval committee will determine the most suitable option for you

NEWS

HCC Fall Advocacy Days- A Perspective from Janice King

by Andrea Palladino https://www.hemophiliaca.org/hcc-fall-advocacy-days-a-perspective-from-janice-hargraves/

My journey as an advocate for hemophilia is deeply personal—rooted in love, loss, and an unyielding hope for the future. My husband, Howard, was one of four male members of the King family living with hemophilia. Growing up in Texas, his treatment options were limited to plasma transfusions, which were often inaccessible and carried significant risks. However, in the late 1970s, our decision to move to California was life-changing for Howard and ultimately, for our family.

Howard was referred to the University of California Davis Medical Center (UCDMC), which at the time was a beacon of hope for individuals with bleeding disorders. The center's state-of-the-art research, innovative treatments, and compassionate medical staff gave Howard access to the care he desperately needed. This not only improved his quality of life but also extended it, allowing us to share many beautiful years together.

Howard passed away in 2016, but his legacy of resilience continues to inspire me. Today, my grandson carries the same diagnosis, which has reignited my passion for advocacy. I am proud to be involved with the Hemophilia Council of California (HCC), an organization that is making a profound difference in the lives of individuals and families affected by hemophilia and other bleeding disorders.

A Weekend of Advocacy and Community

Last October, I had the honor of attending two significant events hosted by the HCC. These gatherings not only reaffirmed my commitment to the cause but also highlighted the incredible work being done by advocates, healthcare professionals, and legislators.

continued on page 7

continued from page 6

October 6, 2024: A Celebration of Advocacy

The Fall Advocacy Days Training Dinner took place in a lovely Bay Area restaurant, where families, friends, and advocates gathered to celebrate the HCC's contributions. It was heartwarming to hear participants share their personal stories about how the organization has positively impacted their lives.

Many spoke about the advancements in treatment modalities that have given them the opportunity to live fuller, more productive lives. We watched a compelling video that detailed the efficacy of a new medication for hemophilia, underscoring how far treatment has come since Howard's early years. *The evening was a testament to the power of advocacy and the importance of community support.*

October 7, 2024: Advocating at the District Offices

The second event brought us to the district office of California State Senator Steve Glazer. Although the senator was unable to attend due to a special session, my daughter, Tiffany King-Hargraves, and I, along with Ashley Gregory of HFNC, met with his representative.

Our meeting was focused and productive. We shared our hopes for continued support and funding for the HCC, emphasizing the critical role the organization plays in advocating for individuals with bleeding disorders. The senator's representative listened attentively, and we left feeling hopeful that our voices would be heard in the upcoming legislative session.

Looking Ahead

My advocacy journey is deeply tied to my family's story, but it's also part of a larger mission to ensure that no one living with hemophilia feels alone or underserved. Organizations like the HCC are vital in pushing for policies, funding, and research that improve lives.

As I reflect on Howard's legacy and my grandson's future, I am filled with gratitude for the progress we've made and determination for the work that lies ahead. Advocacy is not just about speaking up—it's about creating a world where everyone, regardless of their health challenges, has the opportunity to thrive.

To those who are affected by hemophilia, whether directly or indirectly, know that you are part of a strong, resilient community. Together, we can continue to advocate for better treatments, greater awareness, and a brighter future for all.

Welcome, Aspiring Wizards, to the Magical World of

Camp Hemotion 2025!

For Families Affected By Bleeding Disorders

Harry Potter Themed!

SCAN ME!

The Hemophilia Foundation of Northern California
FOR ALL BLEEDING DISORDERS

Register Now At:
hemofoundation.org/events

A Week of Nature, Adventure & Magic Awaits You!

Camp Dates:
Sunday, June 22-
Saturday, June 28

Financial Aid Available!
Contact HFNC at (510) 658-3324 (ext. 1012) or
outreach@hemofoundation.org with any questions!

HYMPAVZI™
marstacimab-hncq
injection | 150 mg/mL

Scan the QR code to sign up for updates at **HYMPAVZI.com**

For routine prophylaxis in patients 12 years and older with hemophilia A or B without inhibitors

NOW APPROVED

Not actual size.

Introducing HYMPAVZI—**a once-weekly subcutaneous** prophylactic treatment that comes in a **fixed-dose,* prefilled pen**

*Your first dose (loading dose) of HYMPAVZI is 300 mg (two 150 mg injections). Then you will inject a weekly (maintenance) dose consisting of 1 or 2 injections as prescribed by your healthcare provider. If more than one injection is required to deliver a complete dose, administer each injection at a different injection site.

What is HYMPAVZI?

HYMPAVZI is a prescription medicine used to prevent or reduce the frequency of bleeding episodes in adults and children 12 years of age and older with hemophilia A without factor VIII inhibitors or hemophilia B without factor IX inhibitors.

It is not known if HYMPAVZI is safe and effective in children younger than 12 years old.

IMPORTANT SAFETY INFORMATION

Important: Before you start using HYMPAVZI, it is very important to talk to your healthcare provider about using factor VIII and factor IX products (products that help blood clot but work in a different way than HYMPAVZI). You may need to use factor VIII or factor IX medicines to treat episodes of breakthrough bleeding during treatment with HYMPAVZI. Carefully follow your healthcare provider's instructions regarding when to use factor VIII or factor IX medicines and the prescribed dose during your treatment with HYMPAVZI.

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

- have a planned surgery. Your healthcare provider may stop treatment with HYMPAVZI before your surgery. Talk to your healthcare provider about when to stop using HYMPAVZI and when to start it again if you have a planned surgery.
- have a severe short-term (acute) illness such as an infection or injury.
- are pregnant or plan to become pregnant. HYMPAVZI may harm your unborn baby.

  Females who are able to become pregnant:
  - Your healthcare provider will do a pregnancy test before you start your treatment with HYMPAVZI.
  - You should use effective birth control (contraception) during treatment with HYMPAVZI and for at least 2 months after the last dose of HYMPAVZI.
  - Tell your healthcare provider right away if you become pregnant or think that you may be pregnant during treatment with HYMPAVZI.
- are breastfeeding or plan to breastfeed. It is not known if HYMPAVZI passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, and herbal supplements.

What are the possible side effects of HYMPAVZI?
HYMPAVZI may cause serious side effects, including:

- **blood clots (thromboembolic events).** HYMPAVZI may increase the risk for your blood to clot. Blood clots may form in blood vessels in your arm, leg, lung, or head and can be life-threatening. Get medical help right away if you develop any of these signs or symptoms of blood clots: swelling or pain in arms or legs; redness or discoloration in your arms or legs; shortness of breath; pain in chest or upper back; fast heart rate; cough up blood; feel faint; headache; numbness in your face; eye pain or swelling; trouble seeing
- **allergic reactions.** Allergic reactions, including rash and itching have happened in people treated with HYMPAVZI. Stop using HYMPAVZI and get medical help right away if you develop any of the following symptoms of a severe allergic reaction: swelling of your face, lips, mouth, or tongue; trouble breathing; wheezing; dizziness or fainting; fast heartbeat or pounding in your chest; sweating

The most common side effects of HYMPAVZI are injection site reactions, headache, and itching.

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

Please see Important Facts about HYMPAVZI on the next page or at www.HYMPAVZI.com

IMPORTANT FACTS

HYMPAVZI™
marstacimab-hncq
injection | 150 mg/mL

Important information: Before you start using HYMPAVZI, it is very important to talk to your healthcare provider about using factor VIII and factor IX products (products that help blood clot but work in a different way than HYMPAVZI). You may need to use factor VIII or factor IX medicines to treat episodes of breakthrough bleeding during treatment with HYMPAVZI. Carefully follow your healthcare provider's instructions regarding when to use factor VIII or factor IX medicines and the prescribed dose during your treatment with HYMPAVZI.

What is HYMPAVZI used for?

HYMPAVZI is a prescription medicine used to prevent or reduce the frequency of bleeding episodes in adults and children 12 years of age and older with hemophilia A without factor VIII inhibitors or hemophilia B without factor IX inhibitors.

It is not known if HYMPAVZI is safe and effective in children younger than 12 years old.

What should I tell my healthcare provider before using HYMPAVZI?

Tell your healthcare provider about all your medical conditions, including if you:

- have a planned surgery. Talk to your healthcare provider about when to stop using HYMPAVZI and when to start it again if you have a planned surgery.
- have a severe short-term (acute) illness such as an infection or injury.
- are pregnant or plan to become pregnant. HYMPAVZI may harm your unborn baby.
  Females who are able to become pregnant:
    - Your healthcare provider will do a pregnancy test before you start your treatment with HYMPAVZI.
    - You should use effective birth control (contraception) during treatment with HYMPAVZI and for 2 months after the last dose of HYMPAVZI.
    - Tell your healthcare provider right away if you become pregnant or think that you may be pregnant during treatment with HYMPAVZI.
- are breastfeeding or plan to breastfeed. It is not known if HYMPAVZI passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, and herbal supplements.

How should I use HYMPAVZI?

See the detailed "Instructions for Use" that comes with your HYMPAVZI for information on how to inject a dose of HYMPAVZI, and how to properly throw away (dispose of) used HYMPAVZI prefilled syringe or HYMPAVZI prefilled pen.

- Use HYMPAVZI exactly as prescribed by your healthcare provider.
- Your healthcare provider will provide information on the treatment of breakthrough bleeding during your treatment with HYMPAVZI. **Do not** use HYMPAVZI to treat breakthrough bleeding.

What warnings should I know about HYMPAVZI?

HYMPAVZI may cause serious side effects, including:

- **blood clots (thromboembolic events).** HYMPAVZI may increase the risk for your blood to clot in blood vessels in your arm, leg, lung, or head and can be life-threatening. Get medical help right away if you develop any of these signs or symptoms of blood clots:
    - swelling or pain in arms or legs
    - redness or discoloration in your arms or legs
    - shortness of breath
    - pain in chest or upper back
    - fast heart rate
    - cough up blood
    - feel faint
    - headache
    - numbness in your face
    - eye pain or swelling
    - trouble seeing
- **allergic reactions.** Allergic reactions, including rash and itching have happened in people treated with HYMPAVZI. Stop using HYMPAVZI and get medical help right away if you develop any of the following symptoms of a severe allergic reaction:
    - swelling of your face, lips, mouth, or tongue
    - trouble breathing
    - wheezing
    - dizziness or fainting
    - fast heartbeat or pounding in your chest
    - sweating

The most common side effects of HYMPAVZI are injection site reactions, including:

- itching
- swelling
- hardening
- redness
- bruising
- pain

Headache and itching were also common side effects. A serious side effect of swelling in the legs happened in one patient in the clinical trial.

These are not all of the possible side effects of HYMPAVZI. Call your doctor for medical advice about side effects. For more information, ask your doctor.

This information is not comprehensive. How to get more information:

- Talk to your health care provider or pharmacist
- Visit www.HYMPAVZI.com to obtain the FDA-approved product labeling
- Call 1-888-HYMPAV-Z

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.

Pfizer

Pfizer Inc., 66 Hudson Blvd East, New York, NY 10001

MEMBER SPOTLIGHT

The Law and You: What To Do If You Find Yourself In Custody as a PWBD*

*(person with a bleeding disorder)

A few facts about what happened to me
Patrick Byron Community Member

I was arrested in Lodi in September 2024 for felony assault with a deadly weapon (firearm) and felony possession of a stolen firearm. I was booked into the San Joaquin county jail and bail was set at $210,000. Both of the charges against me would eventually be dropped, but since the bail was set so insanely high I had to stay in custody until I could see a judge. I was arrested at 6pm Saturday and had to wait until Tuesday for court. At court the judge released me on a promise to appear (no bail). I was released Tuesday night at 11pm.

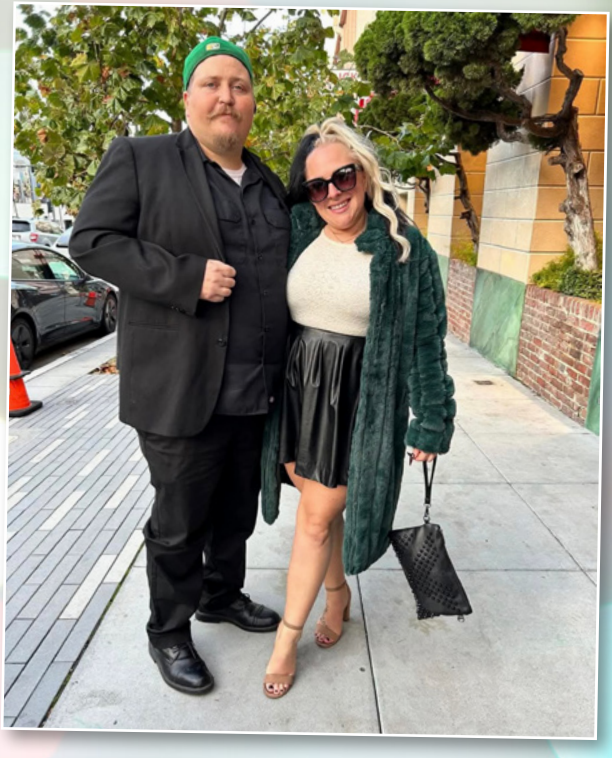
While in custody I was not allowed to take factor for almost 3 days. The jail did not have factor, so I had to have my girlfriend bring it first thing in the morning after my arrest. I explained to the medical staff at the jail that I have hemophilia, what it is, and that i needed to factor immediately because I had just been hand-cuffed and jammed in the back of a cop car (I'm a big guy 5'10 285). My wrists were bruised and my body was sore. Thank God I didn't get in a fight or hit my head prior to or during my arrest I would have likely died. I told them I wa bleeding... they wouldn't do anything until they got my medical records.

At this time I was on 23 hr a day lockdown on Sunday 9am. We got 1 hr rec first chance to make a call since booking. I was able to get my doctor's direct phone number and gave it to them but they refused to call. Locked down til 6pm Monday they still haven't given me factor now I'm worried... my wrists are bruising and I can feel an ankle bleed starting. I can see the factor my girlfriend brought still sitting on the counter. I told them it had to be refrigerated. It says so right on the box. The bag the factors was in also had a prescription on it with the dose and pharmacy and Dr info...they insist on medical records. My doctor said she already sent them and is calling the jail frantically trying to get me treated. Monday night, ankles getting worse; explain to them that if I don't get factor they are going to have to take me to court in a wheelchair. I cry a little and now I'm worried. They look at my ankles both obviously swollen. They look concerned but they just tell me don't worry, we just have to get your medical records... Still no factor.

Tuesday morning 8pm medical check... they prick my finger to check my blood sugar... bad idea... 10 minutes later blood ran down my arm. It's all over the cup they gave me to pee in. I show them they freak out a little. I looked right at the nurse and said that's what's happening inside my ankle right now...i get 2 bandaids & gauze... limp back to the cell still no factor. Tuesday around 10am I get my 1 hr rec. I called my girlfriend and told her to call my doctor and ask her the number she faxed the records to. I go ask the nurse what the fax number is, she tells me, I call my girlfriend, we compare numbers and find out the jail had the wrong number on the form. 15 minutes later they got the fax.

continued on page 13

CUSTODY *continued from page 12*



1 hour before court they come to my cell and tell me they got the records and they are going to bring me the factor to give to myself. I tell them it's intravenous and is supposed to be sterile. The cell smells disgusting like piss, there is stuff smeared on the walls, no soap to even wash your hands. They agreed to bring me to the nurse station to let me mix it and give it to myself. They handed me 1 box (2500 units) that had been left on the counter since Sunday. I explained to them I had an active bleed and it has been 3 days since I had an infusion. I'm severe, less than 1%, with an 8hr half life, my factor levels were at zero and I needed another box. They looked at me like I was speaking another language and gave me another box of factor. I mix the factor I take and instantly all the emotions hit me. Relief because I got factor before being cuffed again, put on a jail bus and marched to court and back. But also the realization that I have relied on this medication my whole life and i sort of took it for granted not realizing one day I would be accused of crimes I didn't commit locked in a cell with nothing but the clothes on my back for days and not be allowed to take the medication I need to be able to function and stay alive.

This was my experience. I don't know if it's like this in every jail but I imagine it is. Let's be honest most Dr's have a hard time understanding our needs as patients that's why we all have specialty care physicians. I know for sure that the officers and the medical staff at my county jail did not understand hemophilia, they didn't know how to treat it, they didn't realize the risk not taking factor creates, and they simply defaulted to their standard operating procedure. We just gotta wait for your medical records. No call to my physician, no urgency, just waiting for a fax…?

Thank you for taking the time to read all that. I hope it can give whoever is interested an idea of what happened and help them fix it in the future. In closing…I honestly do not think people with hemophilia should be held in custody simply because they can't afford bail. I should have been released as soon as I was booked with a promise to appear. That's ultimately what the judge ended up doing 3 days later anyway. They risked my life for no reason. Hemophilia especially if not properly treated creates a significant danger to anybody who is incarcerated and a significant liability for our jails and prisons. There is a substantial amount of risk when holding hemophiliacs in custody, and for this reason I do not believe hemophiliacs and other people with severe bleeding disorders should be held in custody unless they have been convicted and found GUILTY of a crime.

I would like to see legislation to ensure people with bleeding disorders are not held in custody pretrial. I would like to ensure that people in similar circumstances are not put in danger and forced to suffer injury like I was.

Thanks

Patrick Byron
Severe Hemophiliac
Former Inmate 0388307
San Joaquin County Jail

continued on page 13

CUSTODY *continued from page 12*

What the LAW says

By Julian Ross

Julian Ross has severe Hemophilia B. He has attended Camp Hemotion since he was 6 years old, as a camper and then counselor. He is happily married, the proud parent of one child, and the cautious feeder of three cats. He is an attorney and has been a deputy public defender for the past twelve years.

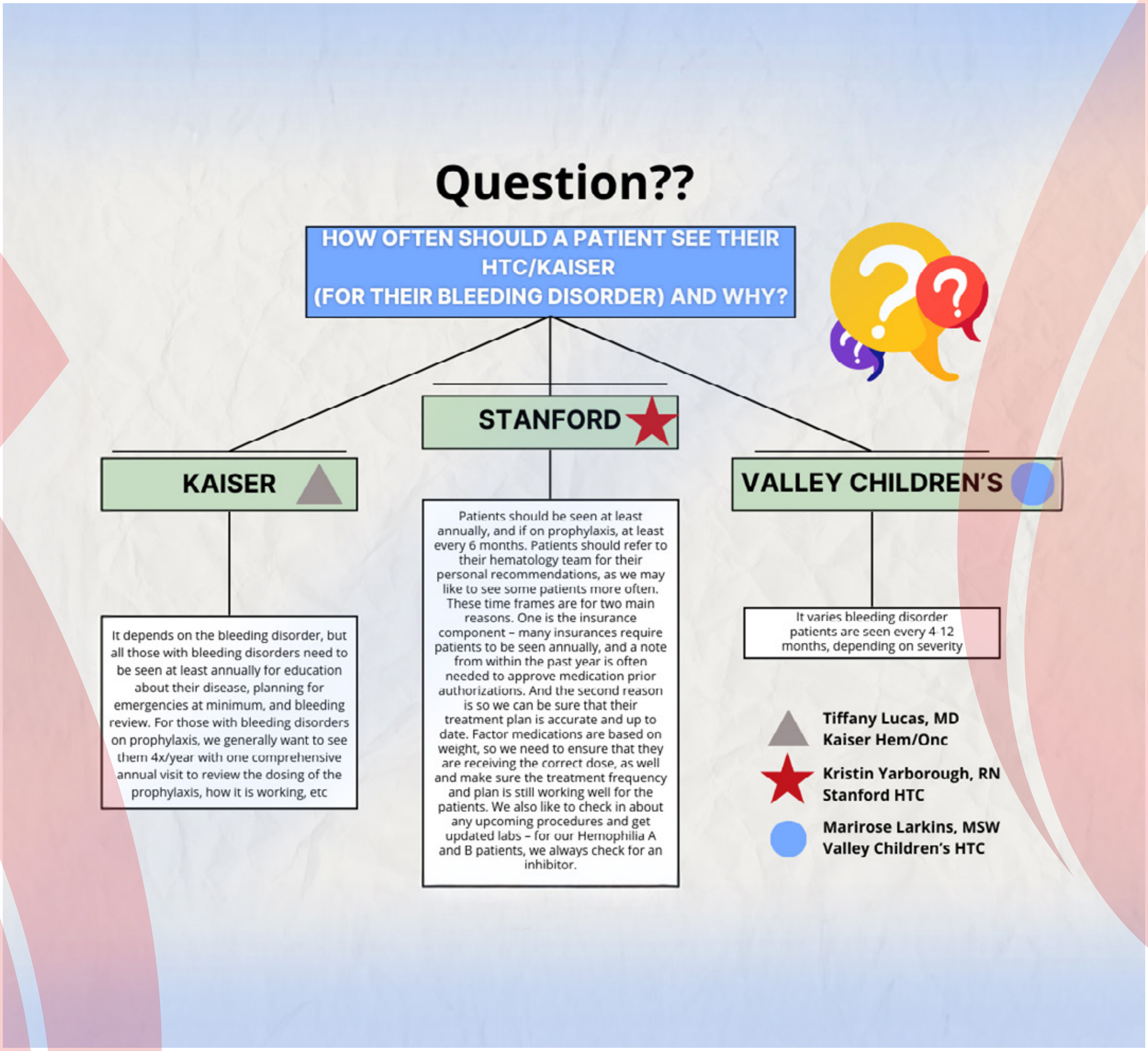
The United States Constitution requires jails and prisons to provide incarcerated individuals with adequate medical care. If someone with a bleeding disorder is incarcerated, they should ask to speak with medical staff inside the jail immediately and inform the medical staff of 1) their bleeding disorder, 2) their medication name, dosage, and frequency of administration, and 3) the name of their treatment center and hematologist.

It is ideal if the incarcerated person has a family member or friend who can contact the treatment center on the person's behalf and notify the treatment center of the individual's incarceration, including the location of the jail or prison.

Providing verification of the individual's bleeding disorder via the treatment center will be very helpful. If available, providing a medical alert necklace or bracelet will also be helpful. In addition to notifying medical staff inside the jail or prison, the incarcerated individual should let their attorney know of their bleeding disorder as soon as possible, and whether the jail or prison is providing the individual's factor (...or other medication...) at the same dosage and at the same intervals as when the individual was not incarcerated. If the jail or prison is not providing adequate care to address the individual's bleeding disorder, the issue can be raised with a judge.

Restricting access to medication is a violation of PENAL CODE Section 67

> “It shall be unlawful to use in the reformatories, institutions, jails, state hospitals or any other state, county, or city institution any cruel, corporal or unusual punishment or to inflict any treatment or allow any lack of care whatever which would injure or impair the health of the prisoner, inmate, or person confined; and punishment by the use of the strait jacket, gag, thumbscrew, shower bath or the tricing up of a prisoner, inmate or person confined is hereby prohibited. Any person who violates the provisions of this section or who aids, abets, or attempts in any way to contribute to the violation of this section shall be guilty of a misdemeanor.”



Question??

HOW OFTEN SHOULD A PATIENT SEE THEIR HTC/KAISER (FOR THEIR BLEEDING DISORDER) AND WHY?

KAISER ▲

It depends on the bleeding disorder, but all those with bleeding disorders need to be seen at least annually for education about their disease, planning for emergencies at minimum, and bleeding review. For those with bleeding disorders on prophylaxis, we generally want to see them 4x/year with one comprehensive annual visit to review the dosing of the prophylaxis, how it is working, etc

STANFORD ★

Patients should be seen at least annually, and if on prophylaxis, at least every 6 months. Patients should refer to their hematology team for their personal recommendations, as we may like to see some patients more often. These time frames are for two main reasons. One is the insurance component – many insurances require patients to be seen annually, and a note from within the past year is often needed to approve medication prior authorizations. And the second reason is so we can be sure that their treatment plan is accurate and up to date. Factor medications are based on weight, so we need to ensure that they are receiving the correct dose, as well and make sure the treatment frequency and plan is still working well for the patients. We also like to check in about any upcoming procedures and get updated labs – for our Hemophilia A and B patients, we always check for an inhibitor.

VALLEY CHILDREN'S ●

It varies bleeding disorder patients are seen every 4-12 months, depending on severity

▲ **Tiffany Lucas, MD**
Kaiser Hem/Onc

★ **Kristin Yarborough, RN**
Stanford HTC

● **Marirose Larkins, MSW**
Valley Children's HTC

Rachel Shegog

My name is Rachel Shegog, though many of you may have been introduced to me as Ashley's son Dylan's fiancé. With that said, you can probably guess how I got my introduction to the bleeding disorder community! When I met Dylan and Ashley, my knowledge of bleeding disorders was very low. I first met the community when I attended a dinner in San Jose where I learned about one of the newer hemophilia drugs. It was fascinating learning more about the doctors and patients behind the drugs. Mostly, the event left me with a good feeling about the community and I knew I wanted to get more involved and be helpful.

Fortunately for me, there's a lot of organization that goes into each of these events and volunteering was as easy as signing up and being told where to go! Ashley knew that Dylan and I both love children, so she signed us up to work at childcare during the next event. Something that was unusual about my introduction to the community was that even before I got to meet all of you, I got the chance to meet your children. I have some experience working with groups of kids, and I remember telling Ashley at the end of that day how kind and calm all the children were to each other. I saw that even through arguments, moments of boredom, and excitement as we waited for the parent's event to end, the children were constantly aware and being gentle around the younger ones. I could tell that this was a special community and I was happy to see how all the children behaved with one another.

As I began attending more events, I got to meet more of the community. This community has been so welcoming to me, even though I am just a friend of the bleeding disorder community and am not a true "blood brother." Just as much as I wanted to help Ashley, I also was in need of a community myself. I was a recent transplant to California and getting involved with HFNC helped me feel a sense of community that I was missing. It feels wonderful to be known and know you all!

Everyone I met made me feel at home and feel safe. One of the first things I noticed about the community was the incredible amount of empathy that the members have. Although I do not have a physical disability, I've had my own experiences in life I know how it feels to be gaslit or disbelieved. In this community, that experience seems to be a common thread. Although our lives have been different, the people here are able to understand and hear me when I talk about what I'm dealing with. That's what I mean when I say this is a safe place to talk- the people here really listen empathetically and have transformed their own negative experiences into a way to be kind and trusting.

I'm looking forward to being even more a part of this community and getting to know you all so much more.
With thanks,

Rachel Shegog

Mark Helm

We are thrilled to introduce Mark Helm as a member of our board of directors. With over 25 years of dedicated involvement in hemophilia support activities across the Fresno area and more than three decades as a pharmacy owner, Mark brings a wealth of experience and passion to our organization.

Mark has lived with hemophilia himself and is the father of an adult son who also has hemophilia, giving him a deeply personal commitment to advancing care and support for our community. Recognized for his warm nature and generous spirit, Mark pioneered one of the first home-care companies focused on hemophilia. His visionary approach led him to hire individuals with hemophilia to deliver factor products—a model that underscored the importance of community-led care and support.

Though now retired, Mark remains active on his Sanger, CA farm and continues to make a significant impact as a valued board member. His sharp business acumen and innovative thinking are invaluable assets to our Finance and Development Committee. Mark's enduring generosity and dedication are a testament to his commitment to the hemophilia community, and we are grateful for his ongoing leadership and insight.

Please join us in thanking Mark for his continued service!

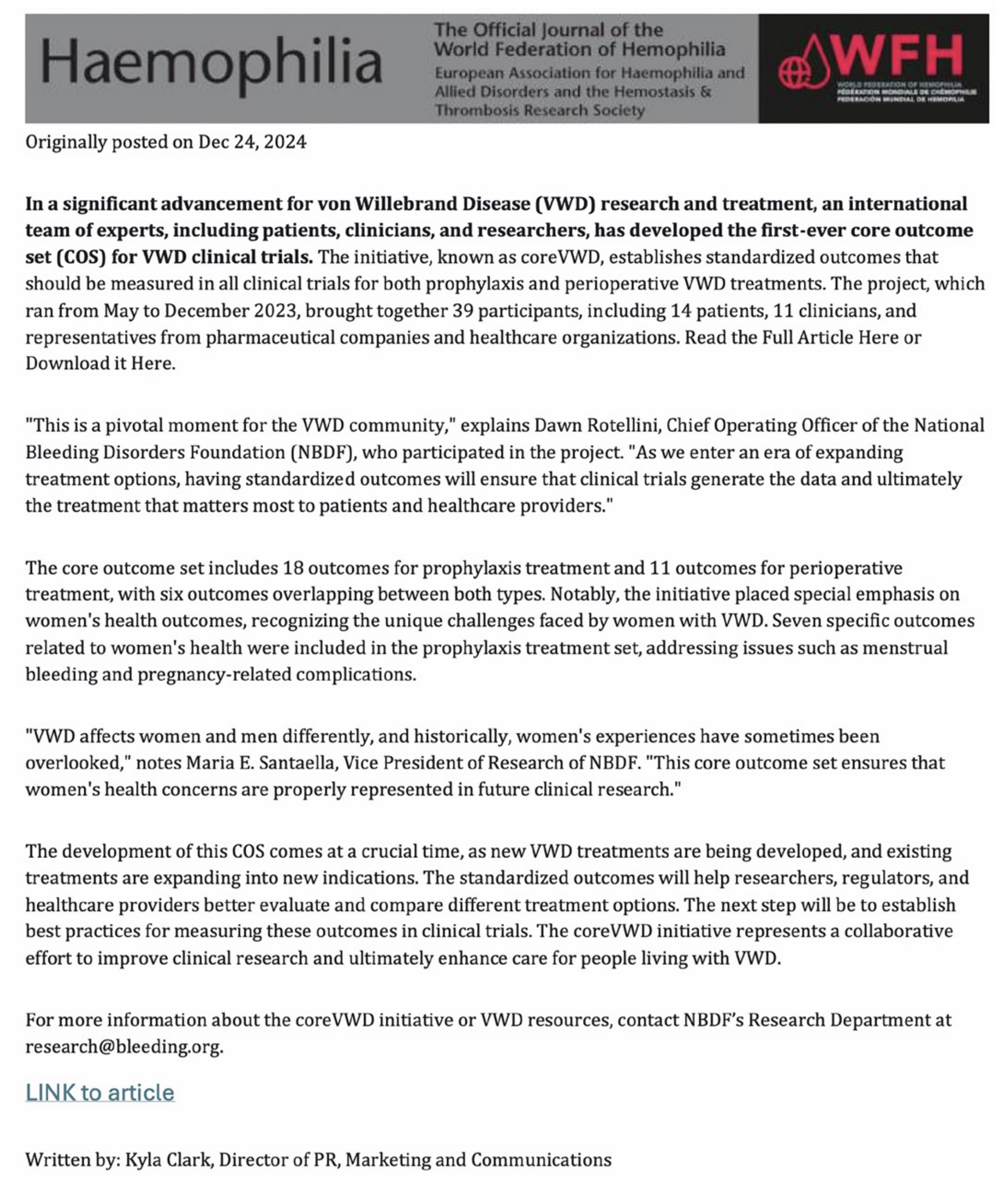
Celebrating the life of

Dr. Marion Koerper

Sunday, March 30, 2025

2 -4 PM

AIDS Memorial Grove
Hemophilia Circle
Golden Gate Park, SF



Haemophilia

The Official Journal of the World Federation of Hemophilia
European Association for Haemophilia and Allied Disorders and the Hemostasis & Thrombosis Research Society

WFH
WORLD FEDERATION OF HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA

Originally posted on Dec 24, 2024

In a significant advancement for von Willebrand Disease (VWD) research and treatment, an international team of experts, including patients, clinicians, and researchers, has developed the first-ever core outcome set (COS) for VWD clinical trials. The initiative, known as coreVWD, establishes standardized outcomes that should be measured in all clinical trials for both prophylaxis and perioperative VWD treatments. The project, which ran from May to December 2023, brought together 39 participants, including 14 patients, 11 clinicians, and representatives from pharmaceutical companies and healthcare organizations. Read the Full Article Here or Download it Here.

"This is a pivotal moment for the VWD community," explains Dawn Rotellini, Chief Operating Officer of the National Bleeding Disorders Foundation (NBDF), who participated in the project. "As we enter an era of expanding treatment options, having standardized outcomes will ensure that clinical trials generate the data and ultimately the treatment that matters most to patients and healthcare providers."

The core outcome set includes 18 outcomes for prophylaxis treatment and 11 outcomes for perioperative treatment, with six outcomes overlapping between both types. Notably, the initiative placed special emphasis on women's health outcomes, recognizing the unique challenges faced by women with VWD. Seven specific outcomes related to women's health were included in the prophylaxis treatment set, addressing issues such as menstrual bleeding and pregnancy-related complications.

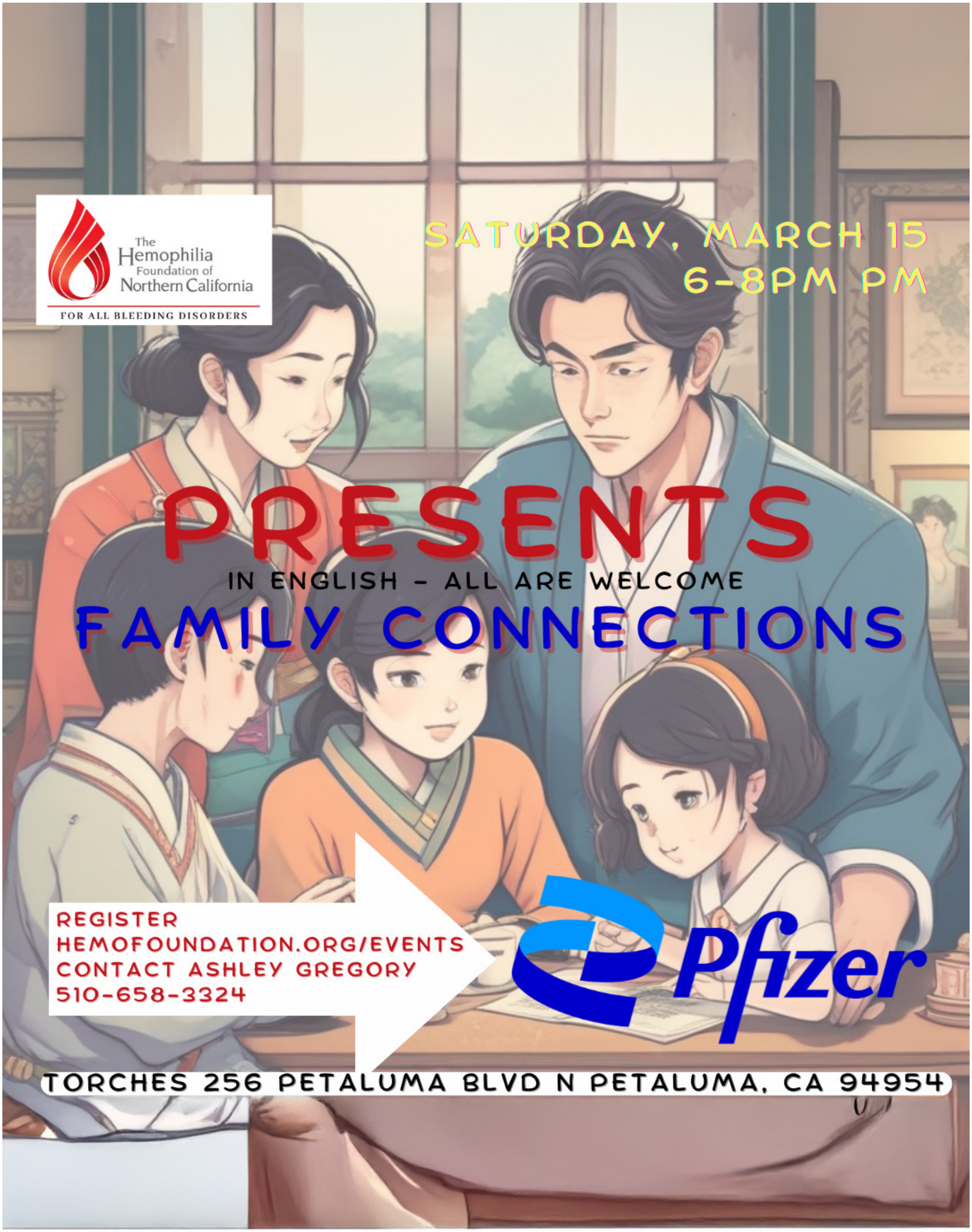
"VWD affects women and men differently, and historically, women's experiences have sometimes been overlooked," notes Maria E. Santaella, Vice President of Research of NBDF. "This core outcome set ensures that women's health concerns are properly represented in future clinical research."

The development of this COS comes at a crucial time, as new VWD treatments are being developed, and existing treatments are expanding into new indications. The standardized outcomes will help researchers, regulators, and healthcare providers better evaluate and compare different treatment options. The next step will be to establish best practices for measuring these outcomes in clinical trials. The coreVWD initiative represents a collaborative effort to improve clinical research and ultimately enhance care for people living with VWD.

For more information about the coreVWD initiative or VWD resources, contact NBDF's Research Department at research@bleeding.org.

LINK to article

Written by: Kyla Clark, Director of PR, Marketing and Communications



The Hemophilia Foundation of Northern California
FOR ALL BLEEDING DISORDERS

SATURDAY, MARCH 15
6-8PM PM

PRESENTS

IN ENGLISH - ALL ARE WELCOME

FAMILY CONNECTIONS

REGISTER
HEMOFOUNDATION.ORG/EVENTS
CONTACT ASHLEY GREGORY
510-658-3324

Pfizer

TORCHES 256 PETALUMA BLVD N PETALUMA, CA 94954

CALENDAR

MARCH 2025

3/1/25-3/31/25	Bleeding Disorders Awareness Month	YOUR City, NorCal
3/5/25-3/7/25	NBDF Washington Days	Washington DC
3/7/25-3/9/25	Family Camp	The Taylor Family Foundation, Camp Arroyo, Livermore, CA
3/15/25-3/18/25	Future Leaders Program HCC	Sacramento
3/17/25	LEG Day	Sacramento
3/11/25	Board Meeting	Virtual
3/27/25-3/30/25	Hemophilia Federation of America Annual Symposium	San Diego, CA
3/30/25	Dr. Marion Koerper Memorial	AIDS Memorial Grove, Hemophilia Circle, SF, CA

APRIL 2025

4/4/25-4/6/25	Western States Region IX Conference	Ko'olina, Hawai'i
4/8/25	Board Meeting	Virtual

MAY 2025

5/3/25	SpringFest/Family Education Event	Mexican Heritage Plaza, San Jose, CA
5/17/25	Board Meeting	In Person, San Francisco, CA
5/26/25	Memorial Day	Holiday HFNC closed

JUNE 2025

6/10/25	Board Meeting	Virtual
6/22/25-6/28/25	Camp Hemotion	Camp Oakhurst, Coarsegold, CA

JULY 2025

7/4/25	Independence Day	Holiday HFNC closed
7/8/25	Board Meeting	Virtual
	Annual Planning	HFNC closed

AUGUST 2025

8/12/225	Board Meeting	Virtual
8/21/25-8/23/25	NBDF Conference	Aurora, CO

SEPTEMBER 2025

9/10/25	Board Meeting	Virtual

OCTOBER 2025

10/11/25	Board Meeting	Virtual

NOVEMBER 2025

11/2/25	Unite for Bleeding Disorders Walk	Heather Farm Park, Walnut Creek, CA
11/11/25	Board Meeting	Virtual
	NBDF Chapter Leadership	TBD
11/27/25	Thanksgiving Holiday	HFNC closed

DECEMBER 2025

12/1/25	World AIDS Day	AIDS Memorial Golden Gate Park San Francisco, CA
12/2/25	Giving Tuesday	Campaign
12/6/25	WinterFest	San Jose
12/14/25	WinterFest	Fresno
12/24/25	Christmas Eve	HFNC closed
12/25/25	Christmas Day	HFNC closed
12/24/25-12/26/25	HFNC closed	HFNC closed

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

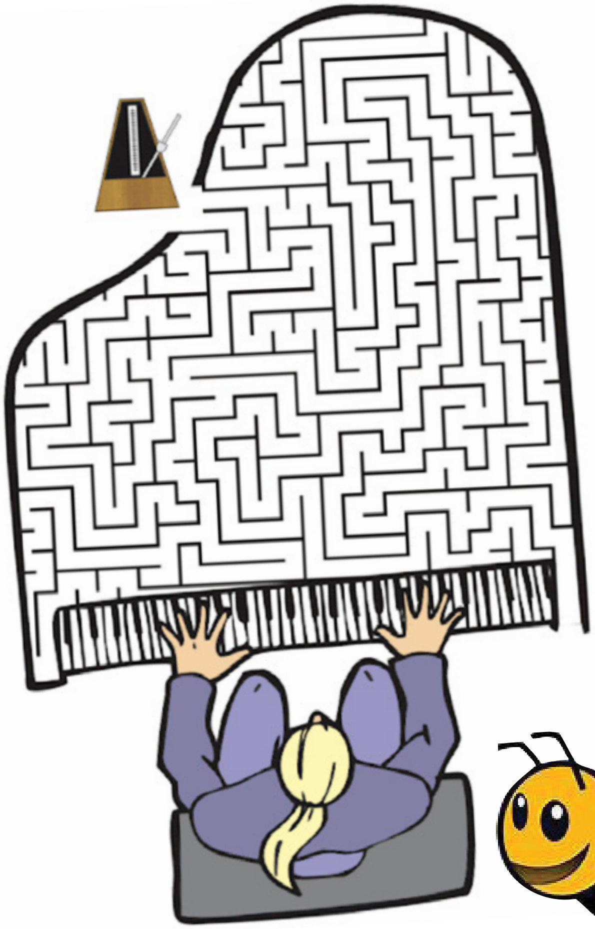
AFFILIATED ORGANIZATIONS

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.bleeding.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/

Kid's Page



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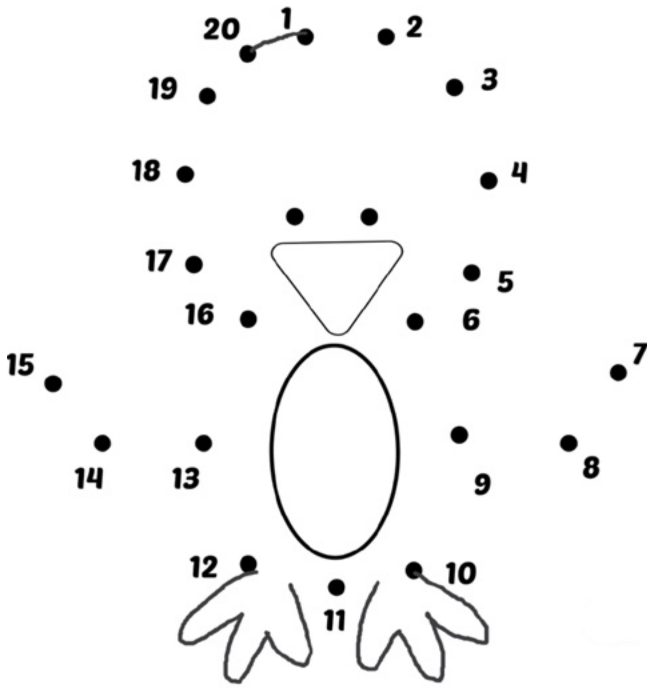
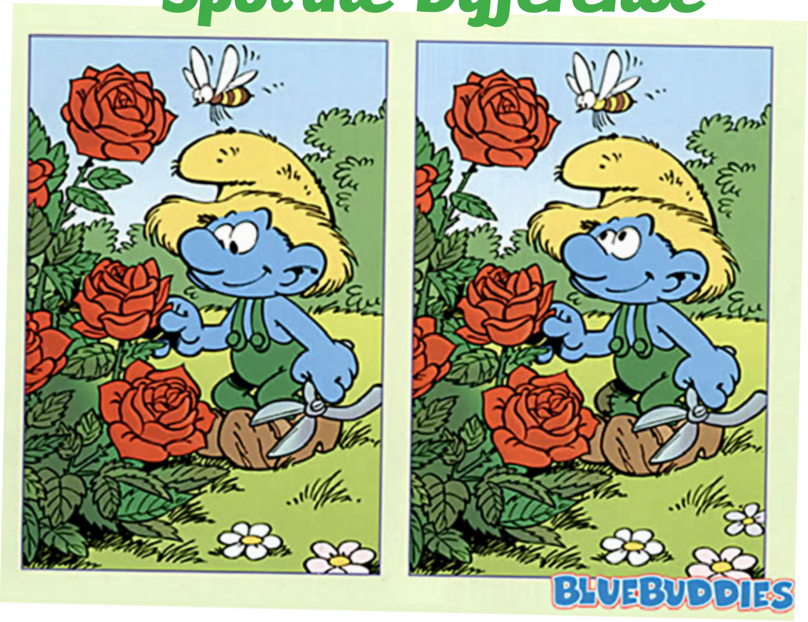
ruby
blocks
heredocs
classes
iterator
module
objects
flexible
each
happy
mutable
lambda
hash
array

DOT TO DOT



Spot the Difference



The Hemophilia Foundation of Northern California

FOR ALL BLEEDING DISORDERS

BREAKING NEWS

MARCH IS BLEEDING DISORDERS AWARENESS MONTH

DECLARE YOUR CITY
@HTTPS://WWW.HEMOFOUNDATION.ORG/SUPPORT/DECLARATION.HTML

The Hemophilia Foundation of Northern California
FOR ALL BLEEDING DISORDERS

SPRINGFEST

EMPOWERING WHOLE-BODY HEALTH FOR FAMILIES WITH BLEEDING DISORDERS

May 3, 2025

Mexican Heritage Plaza, San Jose
8:30 AM - 3:00 PM

Springfest is a special event designed for families affected by bleeding disorders. It's a chance to come together, learn, and focus on overall health and wellness in a welcoming and supportive environment. Attendees will hear about the latest treatment options, discover helpful resources, and gain practical tips for managing daily life with a bleeding disorder. Sessions will cover physical, emotional, and mental well-being, with topics like navigating the healthcare system, self-advocacy, and building resilience. Springfest is all about inclusivity and accessibility, ensuring that every family feels supported, informed, and connected to a caring community.

🎉 Exclusive Perks for Attendees

Stay tuned as we announce the special perks for attendees. When registering, you will choose the perk for your family.

To learn more visit us at:
https://bit.ly/4hWwWFv

Hemophilia
Foundation of
Northern California

FOR ALL BLEEDING DISORDERS

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

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