Infusions

SUMMER 2025

Northern California
Bleeding
Disorders
Foundation

Honoring the Legacy of Dr. Marion Koerper Page 2

IN THIS ISSUE

IN MEMORIAM

Honoring the Legacy of Dr. Marion Koerper

Dr. Marion Koerper, affectionately known as "Dr. K," was a pioneering pediatric hematologist whose dedication transformed the bleeding disorders community.

A Life of Service and Compassion

Founder of UCSF Hemophilia Treatment Center
Established one of the nation's first comprehensive care centers for hemophilia patients.

Co-Founder of Camp Hemotion: In 1978, alongside Susan Karp, RN, Dr. Koerper created a summer camp providing children with bleeding disorders a safe and enriching experience. She served as the camp's medical director for over 30 years.

Advocate During the AIDS Epidemic: Led efforts to ensure blood safety and provided unwavering support to patients during a challenging era.

A Lasting Impact

Dr. Koerper's contributions extended beyond clinical care. She was instrumental in shaping national standards for bleeding disorder treatments and mentored countless healthcare professionals

Continuing Her Legacy on March 30, 2025 a Memorial Service was held at Hemophilia Memorial Circle with a Boulder Dedication Ceremony and Remembrance: Speakers from Left to Right, Top to Bottom - Bobby Wiseman, Robert Blumberg MD (Marion's husband), Dawn Rotellini, Len Valentino MD, Randy Curtis. It was supposed to rain but the sun came through the thick San Francisco fog and revealed the tear soaked cheeks of us all.

In honor of Dr. Koerper's unwavering commitment, donations can be made to the Hemophilia Foundation of Northern California's Camp Hemotion Scholarship Fund, ensuring her vision lives on for future generations.

Help Us Keep Camp Hemotion Open to All

Dear Friends of the Bleeding Disorder Community

I'm reaching out with a personal appeal on behalf of Camp Hemotion—a place that means so much to so many. As you know, Camp Hemotion is more than just a summer camp. It's a safe haven where children and teens with bleeding disorders can experience the joy, freedom, and connection that every child deserves. Here, they build confidence, form lifelong friendships, and are surrounded by a community that truly understands them.

Because of generous supporters like you, we have proudly upheld a vital promise: no child is ever turned away from Camp Hemotion due to their family's financial situation. This is only possible because of community donations and the incredible healthcare professionals who volunteer their time and expertise at camp each year.

But we can't do it without your help.

As we prepare for this summer, we're asking for your support to help cover the cost of camp for each child. The cost per camper is $1650. Every gift—no matter the amount—helps ensure that every camper has the chance to experience the magic of Camp Hemotion.

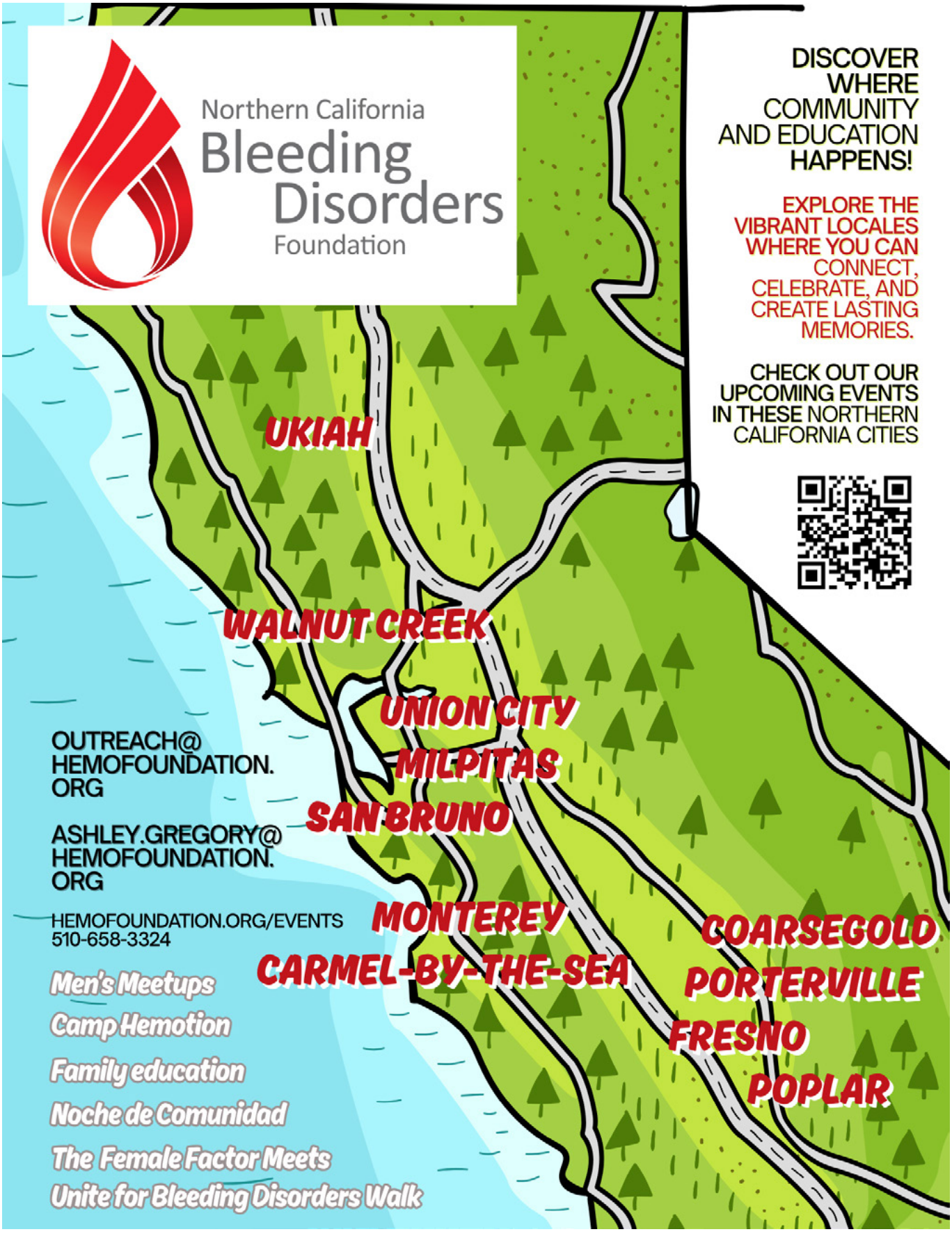
Would you consider donating today to sponsor a camper and help keep this tradition of inclusion alive?

https://www.hemofoundation.org/support/donate.html

On behalf of the Northern California Bleeding Disorders Foundation and all of our campers—thank you. Your past support has made an incredible difference, and we hope we can count on you again this year.

With heartfelt gratitude,

Randy Curtis, *President*
April Steger, *Executive Director*


Northern California
Bleeding
Disorders
Foundation
DISCOVER WHERE COMMUNITY AND EDUCATION HAPPENS!
EXPLORE THE VIBRANT LOCALES WHERE YOU CAN CONNECT, CELEBRATE, AND CREATE LASTING MEMORIES.
CHECK OUT OUR UPCOMING EVENTS IN THESE NORTHERN CALIFORNIA CITIES
UKIAH
WALNUT CREEK
UNION CITY
MILPITAS
SAN BRUNO
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PORTERVILLE
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POPLAR
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Camp Hemotion
Family education
Noche de Comunidad
The Female Factor Meets
Unite for Bleeding Disorders Walk

HYMPAVZI™
marstacimab-hncq
injection | 150 mg/mL

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

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

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

Pfizer

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:

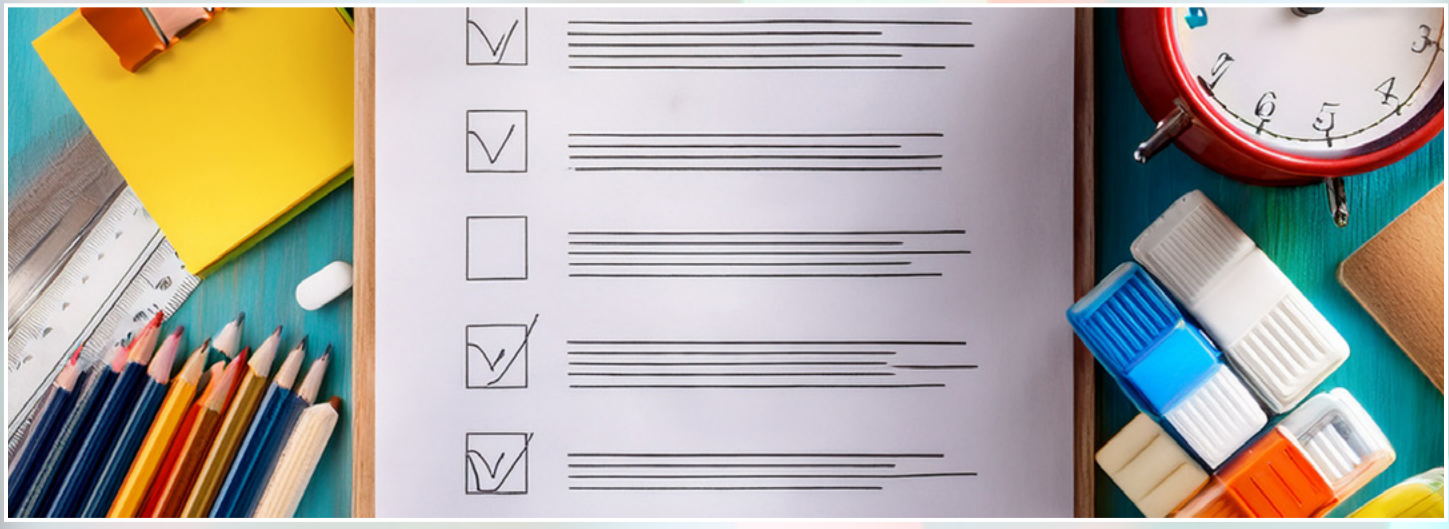
- Talk to your health care provider or pharmacist
- Visit www.HYMPAVZI.com to obtain the FDA-approved product labeling
- Call 1-888-HYMPAV-Z

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

End of School Checklist for Rare and Chronic Families



The end of the school year may seem like it signals an end of busy schedules and structure, however, for families with rare and chronic conditions, it is a point on a spectrum of interactions that need to happen in order for safe and continued care to be in place. Whether it is asthma, a bleeding disorder or comorbid conditions that require a 504, IEP (Individualized Education Plan) or Individualized Health Care Plan (IHCP), families must ensure the following at the end of the school year:

Medications have been picked up last day of school

Meeting has been scheduled for 504/IEP or IHCP with the school principal or other administrator, teacher(s), District Nurse or School Nurse and other appropriate personnel that will need to know about your family member with rare and/or chronic conditions. This meeting is to complete the end of the year goals, discuss any new information that may need to be included in the following year's meeting

Schedule following year's meeting (do it now, the beginning of the year comes on like a landslide and it will be difficult to find time on the calendars of all involved)

Your obligations:

- *Ensure your family members with rare and/or chronic conditions supplies are retrieved from the school.*
- *Ensure a meeting is scheduled to wrap up the end of the school year (sometimes the meeting is to pick up meds, for instance in the case of asthma)*
- *Ensure a meeting is scheduled for the following year at the start of the year*
- *During the summer, refill and replace any supplies that may be aging or soiled. Ensure that the supplies are in good working order and condition for those that may be handling them. Also ensure there are proper disposal receptacles for things like sharps and biohazards. These can be bought at a pharmacy supply store (Walgreens, CVS) and can also be ordered from your specialty pharmacy representative if you have one.*
- *Renew any forms from the school including IHCP's so they are ready and updated when school starts in the fall. Have these at your meeting at the beginning of the year or better yet, email them to the School nurse or health clerk in charge.*

School's obligations:

- *Make available for pick up supplies to family on last day of school*

As you can see, most of the responsibilities lie with the family. It is important that this becomes a regular part of the school year routine in order to ensure smooth transitions year to year and instructional site to instructional site.

HFHEALTHCARE
Infusing Health Right to Your Home

COMPASSIONATE CARE FOR THE BLEEDING DISORDER COMMUNITY

At HF Healthcare, we believe in more than just treating the condition—we focus on empowering and uplifting those affected by bleeding disorders. Liz, a dedicated healthcare provider at HF Healthcare, brings a unique blend of personal and professional experience to the forefront of patient care. As a co-founder of "Music for the Cause," a nonprofit she established with her father to raise awareness and support for the bleeding disorder community, Liz has been deeply connected to this cause for years.

Her motivation stems from a desire to ensure that every individual not only receives the best possible medical care but also the emotional and community support they deserve. With her experience and dedication, Liz and the HF Healthcare team specialize in offering tailored, comprehensive specialty pharmacy services, helping patients navigate their health journey with a holistic, whole-care model.

At HF Healthcare, we're committed to delivering personalized, compassionate care to improve the quality of life for those we serve.

www.hfhealthcare.com
805-981-1171

Liz Seaton-Schauermann

310-422-9621
lizs@hfhealthcare.com

HFHEALTHCARE
Infusing Health Right to Your Home

ATENCIÓN COMPASIVA PARA LA COMUNIDAD CON TRASTORNOS HEMORRÁGICOS

En HF Healthcare, creemos en algo más que tratar la enfermedad: nos centramos en empoderar y animar a las personas afectadas por trastornos hemorrágicos. Liz, una proveedora de atención médica dedicada de HF Healthcare, aporta una combinación única de experiencia personal y profesional a la vanguardia de la atención al paciente. Como cofundadora de "Music for the Cause", una organización sin fines de lucro que estableció con su padre para generar conciencia y apoyo para la comunidad de trastornos hemorrágicos, Liz ha estado profundamente conectada a esta causa durante años.

Su motivación surge del deseo de garantizar que cada individuo no solo reciba la mejor atención médica posible, sino también el apoyo emocional y comunitario que merece. Con su experiencia y dedicación, Liz y el equipo de HF Healthcare se especializan en ofrecer servicios de farmacia especializados integrales y personalizados, ayudando a los pacientes a transitar su camino hacia la salud con un modelo de atención integral y holístico.

En HF Healthcare, estamos comprometidos a brindar atención personalizada y compasiva para mejorar la calidad de vida de quienes servimos.

www.hfhealthcare.com
805-981-1171

Liz Seaton-Schauermann

310-422-9621
lizs@hfhealthcare.com

Northern California Bleeding Disorders Foundation

MEN'S MEETUPS

We've got a solid line-up of events coming up, built to bring us together, strengthen our bonds, and give us space for real conversations and some well-earned fun:

1st Event: The Great Escape - Men's Meetup in Milpitas

Partner: Shelley | SpecialtyCareRx

Saturday, July 19, 2025
12:00 PM – 2:00 PM
123 Great Mall Dr, Milpitas, CA 95035

Register Now: https://bit.ly/4dAAtHX

Tap into your inner tactician with SpecialtyCareRx and your host Pedro P., leading the charge for an adrenaline-pumping Escape Room challenge. Whether you're a strategic thinker or just down to roll with the crew, this is your chance to test your grit and enjoy some time with the boys. A hearty meal will follow!

(Males, ages 18+. Must be diagnosed with a bleeding disorder.)

2nd Event: Men's Meetup with Crystal Higgins – Octapharma

Saturday, August 2, 2025
Time TBD
Location TBD

Crystal is bringing along a Minor League baseball player for a baseball-themed event with stories, inspiration, and plenty of fun. More details to come—stay tuned!

3rd Event: Men's Meetup with Tim Collard – CSL Behring

Date TBD (Likely October)
Time & Location TBD

This session will focus on education tailored specifically for Hemophilia B patients, but all are welcome to attend. We're teaming up with Tim to build something meaningful — be sure to keep your October weekends open!

4th Event: Men's Meetup with Patrick Wagner – Takeda

Date TBD (Likely November)
Time & Location TBD

An end-of-year meetup is in the works with Patrick and the Takeda team. Expect a strong close to the year with time to reflect, relax, and recharge with the crew.

Let's make the time. Let's show-up for each other.

More info to come – reach out to Pedro P. with any questions or to get involved.

510-658-3324, outreach@hemofoundation.org

Northern California Bleeding Disorders Foundation

THE FEMALE FACTOR MEETS

SpecialtyCareRx
Excellence is Our Specialty

THE FEMALE FACTOR
affected and connected

JUNE 14 2025

JUNE 14

MOJOTECHNIQUE YOGA AND LUNCH WITH SHELLEY JAJEH FROM SPECIALTYCARERX

UNION CITY

The Female Factor Meets are like mini-retreats that sprinkle a dash of that fabulous Retreat magic right in your neighborhood! Join us for a cozy gathering where we'll soak up knowledge, chow down on delicious food, and dive into fun activities—hello, community vibes!

Females aged 16 and up,
you're totally invited!
(minors must be accompanied by an adult)

HEMOFOUNDATION.ORG/EVENTS 510-658-3324 HEMOFOUNDATION.ORG

The Female Factor Meets

Females 18+ affected & connected to bleeding disorders

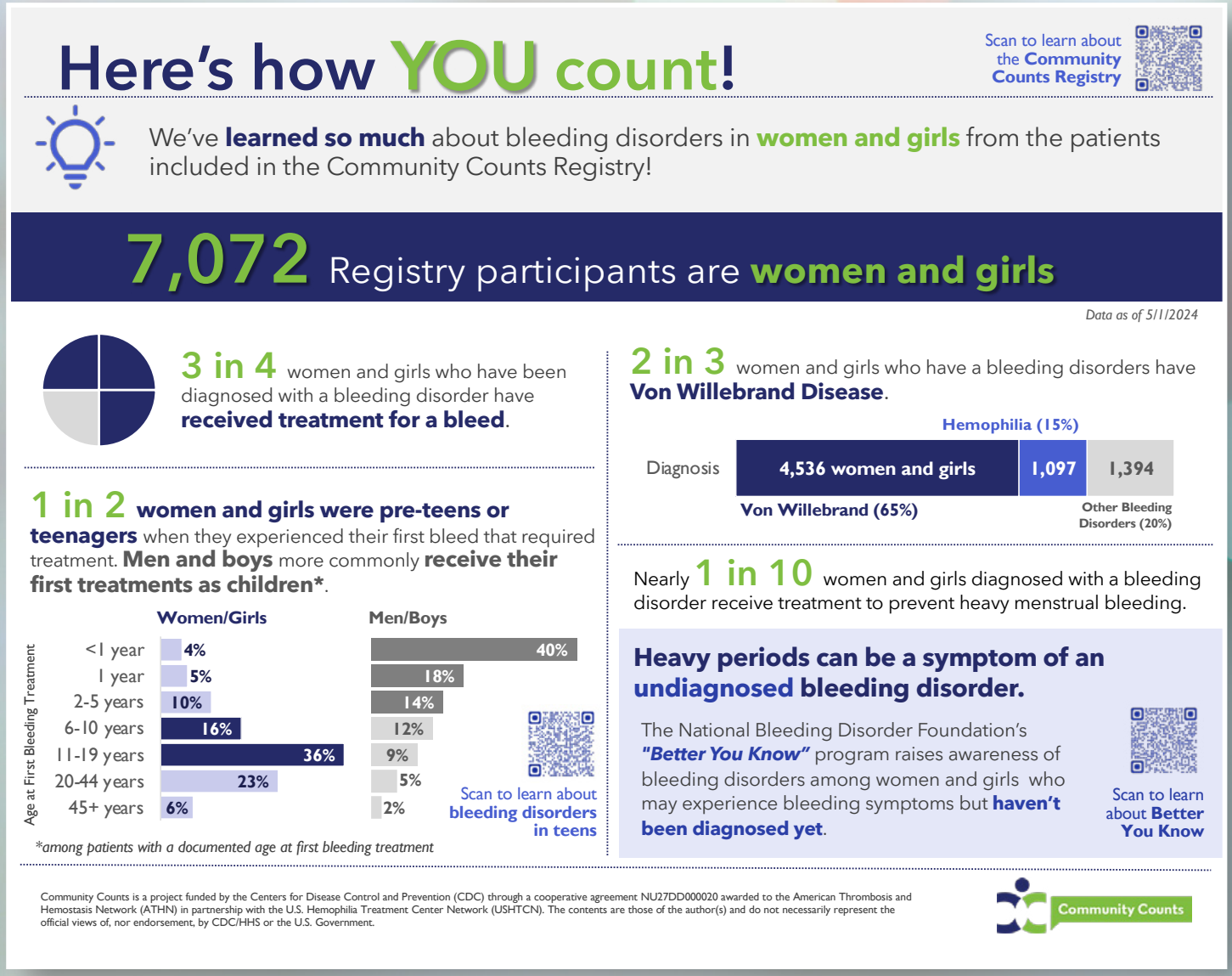
Northern California Bleeding Disorders Foundation

CVS Health

hemofoundation.org/events
510-658-3324
ashley.gregory@hemofoundation.org

UPDATE

NBDF Update: Community Counts Infographic from Washington Days



This year, the National Blood Disorders Foundation (NBDF) made significant strides by including women in discussions with lawmakers, highlighting the concerning disparities in the time it takes for individuals to receive a diagnosis after the onset of symptoms—a disparity that affects our sisters and individuals of all genders. For those who experience bleeding disorders, the challenges can be substantial; however, having two X chromosomes may introduce further obstacles to timely diagnosis, care, and treatment. Thank you, NBDF, for prioritizing the inclusion of women in these critical conversations in 2025.

Sincerely,

NCBDF

Parenting a Child with a Bleeding Disorder

My name is Christine Orr, and I am the mother of John Orr, who is currently 15 years old and was born with Severe Hemophilia Type A. He has an older brother, James, who is not a hemophiliac, and is 19 years old. John's delivery was in a small hospital with no NICU, and there were many complications with his birth and the circumcision. After many consultations, he was taken to Lucille Packard Children's hospital at Stanford and was diagnosed almost immediately. I remembered thinking to myself that the doctor has this all wrong, there is NO way my child is a severe hemophiliac. What is hemophilia? What happens next? Why doesn't his brother have the same condition? We were sent home with minimal information, enough to get by in the meantime, but not with the tools I needed as a mom, now nurse, and future advocate for my son. I had a lot of exploring and learning ahead and am so grateful for the book by Laurie Kelly "Raising a Child with Hemophilia." I read the book cover to cover and finally got an understanding of the disease and treatment, but more than anything, my many emotional and medical hurdles ahead.

John was a wildly active baby, and was having so many joint bleeds, he had a port inserted at nine months. This finally gave us the ability to be autonomous in treating him. Prior, every time he had a bleed, we would have to go to the hospital, which was time consuming and made me feel criticized as a mother. I felt like a failure every time they challenged me on how he had gotten hurt. I was able to use the port to infuse him until third grade, when it ruptured. At that point, insurance was unwilling to insert another, and I had the monumental challenge of learning IV access on him in a matter of days. I hired a local phlebotomist to come to the home, show me all the tricks of the trade, I went across the street to the local fire house and asked the paramedics for tips (they would let me practice on them after every shift), but no matter how successful I was on everyone else, I was afraid to access John. It took longer than I had hoped, but we became a team and were successful. Over the years, he finally ended up on Hemlibra for maintenance and eventually factor as well so that he could also play sports.

From an emotional standpoint, I blamed myself endlessly. I had no idea that I was a carrier. I am one of three girls (I am the only carrier) and my mother and grandmother were both deceased. Through genetic testing, it was confirmed. I was depressed, and not functioning well, it was eating at my marriage, and my parenting overall. All the things his brother had gotten to experience were not options for him, and it was like raising two different species. Shopping carts left him with hematomas, bathtubs, swings, playing at the park, learning to crawl and walk all resulted in injuries. Those were no longer milestones, they were dangerous.

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PARENTING *continued from page 13*

My first encounter with HFNC came during my darkest depression. John was a few months old, and I found Speeders for Bleeders, the former HFNC walk to raise money for Camp Hemotion. At the time, you raised money and walked half of the Oakland marathon. It made me think, if I can do half, maybe I can do the whole thing. If it was not for Speeders for Bleeders, I would not have challenged myself both physically and emotionally to change my "course." I padded up a stroller, and started running every day with my boys, finding some solace in finding my inner strength and physical strength, but also reminding myself to prioritize my mental and physical health. I had become so accustomed to neglecting and punishing myself for this outcome, that I forgot that I am as special as my kids. And if I can't take care of myself, they cannot have a successful role model. I ended up running dozens of marathons, and every finish line, I crossed it knowing that I am stronger than hemophilia.

The hardest part of the hemophilia journey is not the medical part. It is the emotional tax it takes on your child. His life was filled with NO. No, you cannot play soccer, no you cannot play football, no you cannot go to the Tai Kwon Do birthday party, no you cannot be away from me ever, because I must be able to treat you every single day. He was excluded, many parents not comfortable with the responsibility of his diagnosis on a play date or birthday party. His brother was a goalkeeper for soccer, and he looked up to him more than anything, only to be told no by the soccer club, afraid of liability. John started to show the signs of emotional damage and the exclusion emotionally and at a school and athletic level made him

> "The hardest part of the hemophilia journey is not the medical part. It is the emotional tax it takes on your child. His life was filled with NO. No you cannot play soccer, no you cannot play football, no you cannot go to the Tai Kwon Do birthday party, no you cannot be away from me ever, because I have to be able to treat you every single day."

discouraged. John wanted more than ANYTHING to play basketball. And after tremendous push back on him participating, we told him YES. We went to the HTC and asked about using his Hemlibra for maintenance and before any tournament or competition, we use a minor dose of factor for the contact and falls/injuries that would likely occur on the court. If anything, more serious occurred, we would use further doses. He was able to start with the school team and then join multiple AAU leagues and compete like any other kid, his Medic Alert bracelet and hidden padded elbow and knee pads, the only clue that something might be different. As he played more basketball and got more first, we noticed that not only was he proud and confident, but his joints were also stronger, and his bleeds started to be reduced!

In eighth grade he was elected school president, played basketball competitively, and could do all the things that we thought would never be possible. He could go to Great America and ride the rollercoasters, travel to Camp Hemotion (what an AMAZING break for me, not worrying about his safety - for the first time in his entire life I slept without worrying), go on the

continued on page 15

PARENTING *continued from page 14*

school trip to DC (did his own meds), lift weights, throw discus and shot put for the high school track team, and had only the restrictions that he put on himself. What we have learned is that if he lives as a victim to the diagnosis and if I am a victim to the diagnosis, we will be victims in life. It was up to us to find the solutions, and he lives a limitless life.

Camp Hemotion was one of the most valuable weeks of his entire life. For the first time ever, he was not the outcast but part of the NORM! He was surrounded by happiness and s uccess. As well, he had tremendous role models in the counselors and junior counselors. He came home with a new light shining and hope that there is SO much more out in life, that he absolutely can accomplish, hemophilia is something that he HAS not who he IS. He is more than a diagnosis.

The summer before high school, he told me that it was time for him to be more independent, not lean on me for all his support and treatment. He learned self-infusion at the HTC with our nurse (before he was doing only the Hemlibra alone). We reached out to the HTC at LPCH at Stanford, and they said, this would be a GREAT time to go to family camp and share your story, advocate for teens, and help them have the confidence to take charge of their emotional and medical health. The greatest experience ever, is family camp with HFNC.

John and I worked with the 12–17-year-olds, sharing stories and teaching kids how to play basketball, climb a rock wall, zip line, but most importantly were evenings and afternoons talking to one another and sharing stories. I was able to talk to so many new parents and encourage them that life is going to be ok, you will find ways to pivot, and it is not the diagnosis that is a handicap, but a way to find your inner strengths. There is nothing that I look forward to more, than working with HFNC at the walk this fall and family camp, as well as many other opportunities in the future. I was afraid to reach out and go to these big social events when John was little and if I can do one thing, it is to find a way to reach every parent out there and bring them to these opportunities to share and not feel desolate and alone. When John and I pulled out of the parking lot from family camp, we were waving like crazy Muppets at all the new friends we had made only two days before, and who will be friends forever going forward. Without HFNC I am not sure that we would be on this amazing trajectory, they have given us endless resources to be part of a nurturing and supportive community.

Family Camp

by John Orr

My name is John Orr, and I am a 15-year-old severe hemophiliac. My mom has always been the person I go to when I have questions or concerns about my condition, but at this point, I know just about all there is to know about it. I remember during those dreadful hospital visits where the nurses checked that the blood in my body was functioning correctly, they often suggested that I attend "Camp Hemotion," and I never thought much of it; I thought, "I hate my condition, why would I want to be surrounded by it?" One summer I decided I'd give it a shot, and it ended up being an amazing decision. I met endless enjoyable people, who all related to me in a way I've never felt before. It felt amazing to be relatively careless about my condition since everyone around me mentored me and connected with me. Reflecting on how this experience made me feel, this February of 2025, I decided I strived to be one of the people I looked up to at camp-- my mom and I signed up for family camp and volunteered for kids of all ages, helping them grasp the love for the bleeder community rather than hating the idea of having an uncontrollable condition. I will always remember the warmth I felt in my chest after leaving the campsite that weekend. The warmth that was fueled by the community I just bonded with, and the warmth of knowing I helped people out even if in just the slightest way. This led me to sign up for the junior counselor position at Camp Hemotion since it meant I could reunite with the bleeding community and help other kids in my shoes feel the same warmth I felt. You see, this community is an opportunity for me to give back to everyone who has helped me along my hemophilia journey. I believe that this is my chance to become someone that a kid looks up to at Camp Hemotion, or simply someone behind a screen who writes a page about why you should embrace your condition. I believe that no matter what your condition may stop you from doing, it doesn't stop you from finding the positivity in it; in my case, I found HFNC to help me cope and reconstruct my view on hemophilia. No matter how dark your tunnel might be, there is always light at the end, even if that light is simply comforting a kid who is struggling with the same issues you faced.

HFNC goes to School

Sunnyvale, CA (ages 7-9)

clotting cascade demo

Unite Pinwheels project

How to be a good helper to all our friends in school

Factor mixing demo

Principal, nurse, mom were there

Scarlett Peepe

At just three years old I was diagnosed with a platelet storage pool deficiency, along with my mom who had been experiencing the symptoms for her entire life. This means that this diagnosis has always been a big part of my family and personal life. Even though my mom and I had gotten a diagnosis, we still weren't provided access to infusions and only a limited number of medications that could help minimize the symptoms of a bleed. So, I learned to live and thrive with it, helping educate those in my life and finding a community and myself along the way. Throughout elementary school, I was unable to run on the play structure with my peers due to being a clumsy child and not being able to risk getting hurt.

So, my mom and I found different ways to spend my time. We decided that during recess, I would take some friends to the library, where we would draw, play board games, and read books together. This opportunity gave me a love for reading that I still have to this day and taught me various outlets for creativity. Since I have always been very open about my bleeding disorder with my peers and was able to properly educate them, I never felt unsafe or left out.

It was during the beginning of elementary school that I also started to become involved in the Northern California Bleeding Disorders Foundation (NCBDF) and was given the opportunity to learn about others in the community who have dealt with the same struggles as me and use that information to teach others about our bleeding disorders. At events like Family Camp, The Walk, and Camp Hemotion, I met kids my age who were familiar with my struggles. Some of them had Von Willebrand Disease, Hemophilia, or were carriers of bleeding disorders. I learned from each of my friends about their different bleeding disorders, and while they varied, it felt like we were united every time we shared these experiences.

I felt inspired by those who spoke about their medical journeys at these events, to the point where I began asking if I could do the same and began to do so in front of my class and at these NCBDF events. Even though I had gained the confidence to teach my peers about my bleeding disorder, there were still activities that I was simply unable to partake in. Around fourth grade many of my friends started to become involved in extracurriculars outside of school including softball, soccer, and basketball, all of which I was unable to participate in because of my bleeding disorder. So, my mom, with insight from other parents from NCBDF, found other ways I could have fun expressing myself outside of school.

I began playing tennis, a sport where I didn't have the risk of another person bumping into me and performing in musicals at a local children's theater since I love to sing. While I still enjoy participating in both activities in high school, musical theater is where I can be my true self and feel unstoppable. If I hadn't been diagnosed with a platelet storage pool deficiency, I might have started playing soccer with all the other kids in my class. I might never have found my true passion if I hadn't been forced to look for unique ways to spend my time. Of course, there has always been a constant fear of getting hurt and a cautionary thought process in the back of my mind, but that has never stopped me from living spontaneously and having a normal high school experience. If anything, I think my hyper awareness and being open about my disorder have made high school even more enjoyable since my friends help me have fun without ever feeling unsafe. I also don't feel peer pressured into doing dangerous things that make me uncomfortable, as I surround myself with people who are now educated about this disorder.

I have continued this mentality of teaching those around me about my condition throughout my life as a teenager and have been given opportunities to be a leader, including my experience as a junior counselor at Camp Hemotion. My goal is to give young people with bleeding disorders the courage to use their voices to advocate for their medical needs and for others. When given the opportunity, I will always show young bleeders how powerful their voices can be. The best way to do that is through example, which is why I take the task of speaking out so seriously. So, even though the years have been filled with some poking and prodding, I would never change the life I was given.

My diagnosis has opened doors to opportunities performing on stage and given me the confidence to share my experiences as a bleeder with others. I was always taught that no matter what life throws at you, it is important to never let it take you down. I am, and will always be, a bleeder, and I will forever be grateful and embrace this beautiful life I have been given.

Who should patients contact at the HTC for their everyday needs and for those "uh-oh" emergencies?

Question??

WHO SHOULD PATIENTS CONTACT AT THE HTC FOR THEIR EVERYDAY NEEDS AND FOR THOSE "UH-OH" EMERGENCIES?

KAISER

You should review who to call for various circumstances at least **every year** at your comprehensive visits. At the Kaiser Oakland group, we have a 24 hour emergency number that connects with the doctors directly on nights and weekends and is connected with a nurse or physician provider during the day.

Tiffany L. Lucas, MD
Kaiser Oakland Hematology Clinic
Medical Director
Northern California Bleeding Disorders Foundation

Tiffany Lucas, MD
Kaiser Hem/Onc

Bridging Borders: A Life-Saving Connection

A Father's Urgent Call

When a local father contacted the Northern California Bleeding Disorders Foundation (NCBDF) during business hours, he was deeply concerned. His adult son, currently in Mexico with his mother, required emergency surgery but had no access to clotting factor—a critical need in such situations.

Global Community in Action

NCBDF promptly connected with Save One Life, a nonprofit organization dedicated to providing support and resources to individuals with bleeding disorders in developing countries. Through this collaboration, NCBDF identified a local contact affiliated with Save One Life in Mexico and shared this information with the concerned father.

A Successful Outcome

Thanks to these swift actions, the father established contact with the Save One Life ambassador in Mexico. They successfully located the necessary clotting factor, ensuring the young man received the treatment he needed. The surgery was a success.

United by Compassion

This experience underscores the strength and unity of our global bleeding disorders community. At NCBDF, we are proud to be part of a network that transcends borders and language barriers, ensuring that life-saving treatments are accessible to those in need.

NATIONAL BLEEDING DISORDERS FOUNDATION

Innovate | Educate | Advocate

MASAC Medical Advisory #: 430

Sanofi is notifying healthcare professionals about a voluntary recall of one lot (# EY0330) of ALTUVIIIO [antihemophilic factor (recombinant), Fc-VWF-XTEN] after it came to our attention that the label contains erroneous text regarding product dose potency.

Overview of situation
ALTUVIIIO lot #EY0330 of 2000 IU nominal vial potency was erroneously labelled with an actual potency of 2132 IU/mg on the finished product and cartons, instead of the correct value of 1811 IU/vial. The nominal value of 2000 IU/vial is correct and the actual potency is still within FDA-approved manufacturing specifications.

Prescriber Action
The dose of ALTUVIIIO lot #EY0330 is consistent with the recommended dosing in the USPI and is not expected to have a clinical impact on patients who are on a prophylactic regimen, as the FVIII activity levels should remain in the protective range to prevent spontaneous bleeding.

Please work with your pharmacy and your distributors to notify any of your patients who may have received this lot of ALTUVIIIO and instruct them to discontinue use of and return all product from this lot. Please note that the pharmacies have been notified about the recall. If your patient needs treatment before receiving replacement product, the dose should be calculated based on vial potency of 1811 IU/vial and/or per clinical judgement.

Background: Therapeutic Indication
ALTUVIIIO [antihemophilic factor (recombinant), Fc-VWF-XTEN fusion protein-ehtl] is a recombinant DNA-derived, Factor VIII concentrate indicated for use in adults and children with hemophilia A (congenital factor VIII deficiency) for:
• Routine prophylaxis to reduce the frequency of bleeding episodes
• On-demand treatment & control of bleeding episodes
• Perioperative management of bleeding

Cause for the Recall and Mitigating Actions Taken by Sanofi
Sanofi decided to voluntarily recall the batch to avoid having incorrectly labelled units on the market. Out of an abundance of caution, the vials that have been distributed are being recalled and will be replaced.


Northern California
Bleeding
Disorders
Foundation
NOCHE DE COMUNIDAD:
CENA COMUNITARIA PARA FAMILIAS LATINAS!
EDUCACIÓN · COMIDA · FAMILIA
VIERNES, 8 DE AGOSTO | 6:00 PM–8:00 PM
SABROSO RESTAURANTE, POPLAR, CA
¡INSCRÍBETE AHORA!
¡ESCANEA ARRIBA PARA SABER MÁS!
¿Preguntas? Comunícate con Pedro en: outreach@hemofoundation.org o 925-395-0303.
ENTRADA GRATUITA

March 18, 2025

Global Discontinuation of HEMOFIL® M [Antihemophilic Factor (Human), Method M, Monoclonal Purified] and RECOMBINATE® [Antihemophilic Factor (Recombinant)]

Dear Valued Patient,

The purpose of this letter is to inform you that Takeda has decided to globally discontinue HEMOFIL® M [Antihemophilic Factor (Human), Method M, Monoclonal Purified] and RECOMBINATE® [Antihemophilic Factor (Recombinant)].

This was not a decision we made lightly. As the treatment landscape evolves, we decided to discontinue these medicines as hemophilia patients continue to transition to alternate treatment options in the space, including those within our own hematology portfolio. It is important to note there is no quality issue with either HEMOFIL M or RECOMBINATE and that their safety and efficacy remains consistent with the product Prescribing Information.

We understand that this directly impacts you and are here to support the hemophilia community during this transition. **We intend to supply HEMOFIL M and RECOMBINATE to patients already receiving these medicines until inventory is depleted or expired in mid-2026.** Exact timing will vary based on potency and demand.

Transitioning to Alternative Treatment
We recommend beginning to have discussions with your healthcare team to ensure ample time for creating a longer-term, alternative treatment plan.

For more than 70 years, we've pioneered innovations and worked tirelessly to improve the standard of care for hemophilia patients. We are proud to offer alternative treatment options within the Takeda factor VIII portfolio, namely ADVATE® [Antihemophilic Factor (Recombinant)] and ADYNOVATE® [Antihemophilic Factor (Recombinant), PEGylated], that may meet your individual needs and are similar to HEMOFIL M and RECOMBINATE. Please visit ADVATE.com and ADYNOVATE.com for more information.

What is ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated], ADVATE [Antihemophilic Factor (Recombinant)], RECOMBINATE [Antihemophilic Factor (Recombinant)] and HEMOFIL M [Antihemophilic Factor (Human), Method M, Monoclonal Purified]?

- ADYNOVATE and ADVATE are prescription, injectable medicines that are used to replace clotting factor, to help treat and control bleeding in children and adults with hemophilia A (congenital factor VIII deficiency, also called "classic" hemophilia).
- RECOMBINATE and HEMOFIL M are used to prevent and control bleeding in people with hemophilia A.
- Your healthcare provider (HCP) may give you ADYNOVATE, ADVATE or RECOMBINATE when you have surgery.
- ADYNOVATE and ADVATE can each reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE, ADVATE, RECOMBINATE and HEMOFIL M are not used to treat von Willebrand disease.

Randall Curtis Award Winner

Going back to Sacramento for Leg Day was like putting on a comfortable pair of shoes this year. There was a great batch of Future Leaders, fresh out of two days of training. They now have a better understanding of how the government works than most of the citizens in this country. Some of the people there are ones that I only see at Leg Day. They are mostly rural and come a long distance to meet with their legislators. There were also old friends with years of experience. This year was particularly special as they awarded me the Lifetime Achievement Award for Advocacy.

I had been at Washington Days the month before and had brushed up my lobbying skills at the nation's capitol. The program is basically the same. We introduce ourselves at the legislator's office, the Future Leaders tell their personal stories, and then we present "the ask".

Our first ask was to create a patient advocate advisory committee within the Office of Health Care Affordability (OCHA). This is Assembly Bill 278. The idea is to have a patient voice in the OCHA cost-control discussions. Not a big ask.

The second issue was to maintain eligibility and benefits for Medi-Cal, California Children's Services (CCS) and GHPP. These aren't on the chopping block, yet. It helps to remind folks about how important these programs are for people with chronic health issues like bleeding disorders.

Our teams were well coached and our presentations were well received. Many of the staff had seen us before and were familiar with the programs we were concerned about. The staffers asked good questions and understood what our needs are. It is always amazing to see the government process in action and to be part of an effort that makes a difference.

Randy Curtis

May 27, 2025

Dear members of the hemophilia community, We are reaching out to share an important update about the integration of Spark Therapeutics into the Roche Group and to reiterate the commitment to develop a gene therapy as well as other therapeutic advances for people with hemophilia.

In 2019, Spark Therapeutics became a member of the Roche Group. With its extensive resources and worldwide reach, including Genentech in the United States, this partnership aimed to accelerate the discovery, development and delivery of potential gene therapies for more patients affected by a wide range of genetic diseases, including but not limited to hemophilia. On January 30, 2025, Roche, in support of its commitment to address unmet medical needs through cutting-edge science, announced that Spark will become fully integrated into the Roche Group. As a result, in the U.S. Genentech will be the point of contact for the hemophilia A gene therapy program going forward.

While this means that Spark Therapeutics will no longer operate as an independent company, its expertise and knowledge as a leader in gene therapy will be folded into Roche and Genentech, and it will continue in research and manufacturing of medicines. This integration of Spark into the Roche Group supports the long-standing ambition and commitment to provide multiple transformative and reliable treatment options that can address the needs of all people with hemophilia A, their families, and caregivers.

With this change, we want to reinforce that **the Roche Group remains committed to discovering, developing and commercializing innovative treatments for hemophilia.**

In December 2024, we announced the decision to introduce an enhanced function factor VIII variant (SPK-8011QQ) into the hemophilia A gene therapy program. This next-generation gene therapy program is planned to be studied in a Phase 2b clinical trial sponsored by Roche and Genentech. More detailed information about the program is available at the end of this letter.

For those who participated in the Phase 1/2 clinical trial of investigational dirloctocogene samoparvovec (SPK-8011), your participation has been invaluable to advancing hemophilia A gene therapy. The longterm follow-up study will continue, and you will continue to be followed as a study participant. We encourage you to reach out to your clinical trial site with any questions you may have.

Our team wants to take a moment to express our deepest gratitude to you–the patients, families, caregivers, advocacy group leaders, and healthcare providers. Over the years, you have shared your experiences living with hemophilia, we have heard your hopes, questions and curiosities about gene therapy, and you have actively engaged in clinical research–all of which has been essential in advancing gene therapy for hemophilia forward.

Going forward, please direct any questions about the program or Spark integration, to Genentech at infoadvocacyrelations-d@gene.com.
We look forward to continuing this close collaboration through the Genentech Patient Advocacy Relations team.

Sincerely,

Tessa Field, Spark Therapeutics, Director, Patient Advocacy
Gina Truslow, Genentech, Director, Patient Advocacy Relations

Phase 2b Hemophilia A Gene Therapy Clinical Trial
In line with the commitment to bring transformational therapies to patients, the Roche Group is introducing an enhanced function factor VIII variant (SPK-8011QQ) into the hemophilia A gene therapy program.

Current adeno-associated virus (AAV) gene therapies introduce the factor VIII gene to the liver aiming to improve blood clotting for individuals with hemophilia A. By modifying the gene used in our investigational gene therapy, we hope to achieve what the hemophilia community and healthcare providers are looking for in one-time gene therapies, including improved hemostasis and lowered treatment burden.

This decision builds on the results seen in the phase 1/2 study of investigational gene therapy dirloctocogene samoparvovec (SPK-8011), which provided early insights to safety, predictability, and durability using a low-dose approach. This study is investigational and efficacy and safety of dirloctocogene samoparvovec has not been established. We will be leveraging the capsid (delivery vehicle) and scientific learnings from the phase 1/2 program and introducing an enhanced function factor VIII variant with the goal of developing a durable gene therapy that provides effective protection against bleeds, without the need for factor VIII prophylaxis.

As we transition to the enhanced function FVIII variant, we have chosen to discontinue the phase 3 dirloctocogene samoparvovec gene therapy study. The phase 3 was stopped prior to dosing any participants. Stopping the study was not related to safety concerns with dirloctocogene samoparvovec. Participants in the phase 1/2 study of dirloctocogene samoparvovec will continue to receive long-term follow-up and monitoring.

We are excited about the potential to advance hemophilia A gene therapy through a next-generation program. This next generation gene therapy program is planned to be studied in a Phase 2b clinical trial sponsored by Roche and Genentech. The phase 2b study will allow us an opportunity to gather safety data before starting a larger phase 3 study of the enhanced function variant.

CALENDAR

JUNE 2025

6/7/25	Pizza Party! Sign up to Register for Camp Hemotion	Dave and Buster's Concord, CA
6/10/25	Board Meeting	Virtual
6/14/25	The Female Factor Meets	The Mojo Technique Union City
6/21/25-6/28/25	Camp Hemotion **JC/AC's**	Camp Oakhurst, Coarsegold, CA
6/22/25-6/28/25	Camp Hemotion **Campers**	Camp Oakhurst, Coarsegold, CA

JULY 2025

7/4/25	Independence Day	Holiday NCBDF closed
7/8/25	Board Meeting	Virtual
7/12/25	The Female Factor Meets	Asilomar, Pacific Grove, CA
7/19/25	Men's Meetup	The Escape Game, Milpitas, CA
7/28/25	Annual Planning/ NCBDF closed	In person

AUGUST 2025

8/2/25	Men's Meetup	To Be Announced, NorCal
8/8/25	Latino Outreach Program	Sabroso Restaurante, Poplar, CA ESPANOL
8/12/225	Board Meeting	Virtual
8/21/25-8/23/25	NBDF Bleeding Disorders Conference	Denver, CO

SEPTEMBER 2025

9/1/25	Labor Day	Holiday NCBDF closed
9/5/25 -9/7/25	Familia de Sangre	Anaheim, CA
9/9/25	Board Meeting	Virtual
9/27/25	Retiros de Mujeres	To Be Announced, NorCal, ESPANOL

OCTOBER 2025

10/14/25	Board Meeting	Virtual
10/16/25	Dinner & Education	Carmel-By-The-Sea, CA
10/26/25	Hemlibra Event	Fresno, CA ESPANOL

NOVEMBER 2025

11/2/25	Unite for Bleeding Disorders Walk	Heather Farm Park, Walnut Creek, CA
11/11/25	Board Meeting	Virtual
11/17/25-11/20/25	NBDF Chapter Leadership	Charlotte, NC
11/27/25-11/28/25	Thanksgiving Holiday	Holiday NCBDF 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	Maggiano's, San Jose, CA
12/7/25	WinterFest	Fresno Breakfast House, Fresno, CA
12/24/25-1/2/26	Winter Break	Holiday NCBDF closed

JANUARY 2026

1/1/2026	New Year's Day	Holiday NCBDF closed

NCBDF Northern California Bleeding Disorders Foundation
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/

Kaiser Oakland Pediatric Hematology/Oncology
https://Kaiser Oakland Pediatric Hematology/Oncology

Northern California Bleeding Disorders Foundation

You're Invited To a MAGICAL

PIZZA PARTY V2

NEED HELP REGISTERING FOR CAMP HEMOTION?

Join us on Saturday, June 7th from 12pm-2pm at Dave & Buster's - Concord!

- Get help registering your child using our laptops on the spot!
- Ask questions about camp
- Enjoy a slice of pizza & play games while you're here!
- First 3 families to arrive in-person get a $20 game card! *

*Must be a new Camp Hemotion registrant for 2025**

INTERESTED? SCAN BELOW TO LEARN MORE & RSVP!

Questions?
Reach out to Pedro at:
925-395-0303

FREE ENTRY

Northern California Bleeding Disorders Foundation

Northern California Bleeding Disorders Foundation (NCBDF) does not endorse any particular pharmaceutical manufacturer or home care company.

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

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

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

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