

Infusions

FALL 2025



Unite for Bleeding Disorders Walk

2024

**8 AM Reg, 9 AM Start,
November 2, 2025
Walnut Creek, CA**

*Walk with us to support the
bleeding disorders community!*

Unite
for Bleeding Disorders

Northern California
Bleeding

Disorders
Foundation

ABOUT OUR NEW LOGO... See on Page 2

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NorCalBDF's Dedication to an Inclusive Community



At the Northern California Bleeding Disorders Foundation (NorCalBDF), our mission is rooted in supporting and empowering every person affected by bleeding disorders. We are committed to serving Californians of all races, religions, genders, sexual orientations, ages, and immigration statuses. Through education, advocacy, and community engagement, we strive to foster an environment of diversity, equity, and inclusion. By encouraging respectful dialogue and understanding among people of varied backgrounds, we work to ensure that all individuals with bleeding disorders have equitable access to quality care and treatment.

IMMIGRATION AND LEGAL SUPPORT RESOURCES

If you, your family, or someone you know is in need of immigration assistance, the following resources may be helpful (courtesy of the American Immigration Lawyers Association and Catholic Charities of Northwest California):

Know Your Rights: If ICE Visits Your Home (AILA):

<https://www.aila.org/library/know-your-rights-if-ice-visits-your-home-english>

Understand Your Rights / Red Card Download:

<https://ccnwc.org/what-we-do/knowyourrights.html>

Catholic Charities of Santa Clara County:

https://www.ccscc.org/immigration-legal-services?utm_source=chatgpt.com&locale=en

Catholic Charities San Francisco:

https://catholiccharitiessf.org/?utm_source=chatgpt.com

Immigration Advocates Network:

https://www.immigrationadvocates.org/nonprofit/legaldirectory/organization.392572-Catholic_Charities_of_the_Diocese_of_Santa_Rosa_Immigration_Program?utm_source=chatgpt.com 🔥

Compromiso de NorCalBDF con una Comunidad Inclusiva



En la Fundación de Trastornos de Sangrado del Norte de California (NorCalBDF), nuestra misión se basa en apoyar y empoderar a todas las personas afectadas por trastornos hemorrágicos. Estamos comprometidos a servir a los californianos de todas las razas, religiones, géneros, orientaciones sexuales, edades y estatus migratorios. A través de la educación, la defensa de derechos y la participación comunitaria, trabajamos para fomentar un entorno de diversidad, equidad e inclusión. Al promover el diálogo respetuoso y el entendimiento entre personas de diversos orígenes, buscamos garantizar que todas las personas con trastornos de sangrado tengan acceso equitativo a una atención médica y tratamiento de calidad.

RECURSOS DE APOYO LEGAL E INMIGRACIÓN

Si tú, tu familia o alguien que conoces necesita asistencia en temas migratorios, los siguientes recursos pueden ser de ayuda (cortesía de la Asociación Estadounidense de Abogados de Inmigración y Caridades Católicas del Noroeste de California):

Conoce tus derechos: Si ICE visita tu hogar (AILA):

<https://www.aila.org/library/knowyourrightsifcevisitsyourhomeenglish>

Conoce tus derechos / Descarga la Tarjeta Roja:

<https://ccnwc.org/whatwedo/knowyourrights.html>

Caridades Católicas del Condado de Santa Clara:

https://www.ccscc.org/immigrationlegalservices?utm_source=chatgpt.com&locale=en

Caridades Católicas de San Francisco: https://catholiccharitiessf.org/?utm_source=chatgpt.com

Red de Defensores de Inmigración:

https://www.immigrationadvocates.org/nonprofit/legaldirectory/organization.392572Catholic_Charities_of_the_Diocese_of_Santa_Rosa_Immigration_Program?utm_source=chatgpt.com 🔥



“Asilomar invited us to pause, breathe deeply, and let the rhythm of the ocean guide us.”

During our time together, we embraced the calm of the coast, shared a delicious meal, and dove into an enlightening discussion on genetics and bleeding disorders. Guided by the compassionate expertise of Ruth Martinez, RN from CVS Health, we explored the many ways genetics shape our experiences—whether we’re new parents navigating uncertainty, individuals seeking answers on a diagnostic journey, or grandparents wondering what the future may hold for the next generation.

Each time we revisit this topic, we discover something new—because genetics doesn’t just inform our past; it shapes our future.

Thank you to everyone who joined us for this special gathering. Here’s to continued learning, shared stories, and community support. 🔥

Upcoming events:

Saturday, September 13, 2025
4-7PM

South San Francisco

Saturday, October 25
11-2PM
Union City

Thursday, November 13
6-8PM
Salinas



THE FEMALE FACTOR
affected and connected

THANK YOU TO OUR 2025

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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



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

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Men's Meetup Highlights & What's Next

Looking back, one of our standout Men's Meetups was the escape room adventure in Milpitas with Specialty-CareRx and Shelley Jajeh. Nine of us came together that night, ready to put our minds to the test and see if we could beat the clock. We laughed, we strategized, and we tackled each puzzle like a true team. There were moments of head-scratching, bursts of excitement when we cracked a tough clue, and plenty of good-natured competition along the way. In the end, it wasn't just about escaping the room—it was about the camaraderie, the connections, and the shared experience that made the night unforgettable. It's these kinds of events that remind us why we do what we do, and why the Men's Meetup tradition continues to grow stronger with each gathering.

More recently, on August 2nd, we hit it out of the park at our Men's Meetup at Payless Batting Cages! Ten guys from the bleeding disorders community—and our special guest speaker living with hemophilia—came together for an evening of connection, conversation, and a few good swings in the cages. Big thanks to Crystal Higgins from Octapharma for making the night even better by coordinating our guest speaker, whose story inspired everyone in the room. We kicked things off with pizza, wings, and drinks before grabbing bats and "swinging for the fences." It was the perfect mix of laughs, camaraderie, and new connections—especially for those joining a men's event for the first time.

Now, we're ready to take that same energy to the next level.

Our next Men's Meetup with CSL Behring is happening on Saturday, October 4th from 12:00–3:00 PM at Top Golf in San Jose. This one's going to be special—CSL is bringing Perry Parker to hang out, swing with us, and share his story as our guest speaker. It's going to be a great mix of fun, friendly competition, and meaningful conversation. Whether you're a golf pro or you've never swung a club before, this is all about connecting, laughing, and enjoying time together. We're aiming for 20–30 guys to join in, so bring your energy, invite a fellow blood brother, and let's make it an afternoon to remember! 🔥



Don't Let Fear Keep You from Care: Guidance for Individuals Worried About Seeking Medical Help



In many communities, individuals may feel anxious about attending medical appointments due to concerns about their immigration status. This fear can prevent people from getting the care they need to stay healthy. If you or someone you love is hesitant to seek healthcare for these reasons, know that there are safe options and resources available.

1. Healthcare Facilities Are Considered Safe Spaces

Hospitals, clinics, and other medical settings are widely recognized as places where enforcement actions are extremely rare. The priority in these spaces is your health and safety, not your legal status. Medical professionals are there to care for you—not to question your background.

2. Telehealth Is Often Available

Many healthcare providers now offer telehealth appointments—by phone or video—so you may be able to speak with a doctor from the comfort and privacy of your home. While not every situation can be handled remotely, many check-ins and follow-ups can be. Contact your provider to see if this is an option for you.

3. Your Information Is Confidential

Medical providers are legally required to protect your personal health information. They do not share your immigration status. You are welcome to ask your clinic how they handle privacy and confidentiality if you have any concerns.

4. Go With Someone You Trust

If you feel uneasy about visiting a clinic in person, you might consider bringing a trusted friend, family member, or community advocate to support you.

5. Local Organizations Can Help

Community-based organizations often offer help connecting people to trustworthy healthcare providers. They may also provide legal information, support services, and referrals to clinics that serve all individuals, regardless of immigration status.

You Deserve to Be Healthy and Safe

Delaying care out of fear can lead to bigger health problems down the line. You have the right to care, to dignity, and to safety. If you're unsure about your options, reach out to a local community clinic or legal aid group for guidance and support. 🔥

No dejes que el miedo te impida recibir atención médica: Guía para personas preocupadas por buscar ayuda médica



En muchas comunidades, algunas personas sienten ansiedad al asistir a citas médicas debido a preocupaciones relacionadas con su estatus migratorio. Este miedo puede impedir que reciban la atención que necesitan para mantenerse saludables. Si tú o alguien a quien amas duda en buscar atención médica por estas razones, es importante saber que existen opciones y recursos seguros disponibles.

1. Los centros de salud se consideran espacios seguros

Los hospitales, clínicas y otros entornos médicos son ampliamente reconocidos como lugares donde las acciones de inmigración son extremadamente raras. La prioridad en estos espacios es tu salud y seguridad, no tu estatus migratorio. Los profesionales de la salud están ahí para cuidarte—no para cuestionar tu situación.

2. Puedes acceder a citas médicas por teléfono o videollamada

Muchos proveedores de salud ahora ofrecen citas por teléfono o videollamada, lo que te permite hablar con un médico desde la comodidad y privacidad de tu hogar. Aunque no todas las situaciones se pueden resolver a distancia, muchos chequeos y seguimientos sí. Comunícate con tu clínica para ver si esta opción está disponible para ti.

3. Tu información es confidencial

Los proveedores de salud tienen la obligación legal de proteger tu información médica personal. No comparten tu estatus migratorio. Si tienes dudas, puedes preguntar en tu clínica cómo manejan la privacidad y la confidencialidad.

4. Ve con alguien de confianza

Si te sientes incómodo al visitar una clínica en persona, considera llevar a un amigo, familiar o defensor comunitario de confianza que te acompañe y te apoye.

5. Las organizaciones locales pueden ayudarte

Muchas organizaciones comunitarias ayudan a conectar a las personas con proveedores de salud confiables. También pueden ofrecer información legal, servicios de apoyo y referencias a clínicas que atienden a todas las personas, sin importar su estatus migratorio.

Tú mereces estar sano y seguro

Retrasar la atención médica por miedo puede causar problemas de salud más graves en el futuro. Tienes derecho a recibir atención, a ser tratado con dignidad y a sentirte seguro. Si no estás seguro de tus opciones, comunícate con una clínica comunitaria o con un grupo de ayuda legal local para recibir orientación y apoyo. 🔥

Medi-Cal Program Changes (2026-2027)

What Medi-Cal Members Need to Know



For most Medi-Cal members, eligibility and benefits will stay the same

This means you will continue to have access to doctor visits, hospital stays, emergency care, prescription drugs, mental health and substance use disorder treatment, preventive services like screenings and immunizations, and long-term care and transportation, when needed. Coverage also includes dental and vision care, as well as other benefits that support your health and well-being.



**JANUARY
2026**

Change for Older Adults and People with Disabilities Asset Limit

Starting **January 1, 2026**, Medi-Cal will once again consider assets (what you own) when reviewing eligibility for seniors and people with disabilities as part of the application and renewal process.

WHO:

Medi-Cal members and applicants whose eligibility is based on age (65+), disability (physical, mental, or developmental), or long-term care needs.

KEY INFORMATION:

- » The **asset limit** is \$130,000 for one person. Each additional household member adds \$65,000 to the asset limit, up to 10 members per household.
- » Assets include bank accounts, cash, and anything over one home and one vehicle.
- » **Some assets don't count**, like the home you live in, one vehicle, household items, and certain savings, like retirement accounts.
- » If you are already a Medi-Cal member, assets will be reviewed at your annual renewal. **Income rules are not changing.**

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**JANUARY
2026**

Changes for Certain Adult Immigrants

Medi-Cal Enrollment Freeze for Undocumented Members 19+

Starting **January 1, 2026**, Medi-Cal will freeze new enrollments for certain adults who are undocumented and do not have a satisfactory immigration status for federal full scope Medi-Cal. This group will no longer be able to newly enroll in full scope Medi-Cal, even if they qualified before under state-funded programs.

WHO:

Californians aged 19 and older, who are not pregnant, who are undocumented, and who qualified for full scope Medi-Cal because of the state-funded Adult Expansions.

KEY INFORMATION:

- » **If you are already enrolled** in full scope Medi-Cal, you will stay covered no matter your immigration status as long as you **complete your annual renewal**. Make sure to renew and use your benefits!
- » If you are part of this group and **lose your coverage**, you **won't be able to sign up again**—except for emergency and pregnancy care.
- » If your coverage stops because of a **late renewal or missing paperwork**, you will have **90 days to fix it** and stay enrolled.
- » Income-eligible **children (0-18) and pregnant people** can enroll in full scope Medi-Cal, no matter their immigration status. Coverage is for the entire pregnancy and one year after the pregnancy ends.



**JULY
2026**

Dental Coverage

Starting **July 1, 2026**, dental benefits will no longer be provided to adult Medi-Cal members who do not have [satisfactory immigration status](#).

WHO:

Californians aged 19 and older who do not have a satisfactory immigration status, including, but not limited to:

- » Green card holders not exempt from the five-year waiting period, who have had their permanent resident status for less than five years.
- » PRUCOL (e.g., with temporary protected status or refugee status).
- » People with no immigration status, but who currently qualify under past Medi-Cal expansions.
- » People enrolled through a trafficking or crime victim assistance program.
- » Lawfully present immigrants who are older than age 20 and not pregnant.

KEY INFORMATION:

- » **Emergency dental care** (such as treatment for severe pain or infection and tooth extractions) **will still be covered for everyone**, no matter their immigration status.
- » **If you are pregnant** and do not have a satisfactory immigration status, you will continue to receive full dental benefits during pregnancy and up to one year after the pregnancy ends.

continued on page 12

**JULY
2027**

Monthly Premiums

Starting **July 1, 2027**, certain adult Medi-Cal members who do not have a [satisfactory immigration status](#) must pay **\$30 per month** to keep full scope Medi-Cal.

WHO:

Californians aged 19-59, who are not pregnant, and who do not have a [satisfactory immigration status](#), including but not limited to:

- » Green card holders subject to the five-year waiting period, who have had their permanent resident status for less than five years.
- » PRUCOL (e.g., with temporary protected status or refugee status).
- » People without federal immigration status who currently qualify under past Medi-Cal expansions.
- » People enrolled through a trafficking or crime victim assistance program.
- » Lawfully present immigrants older than age 20 who are not pregnant.

KEY INFORMATION:

- » Full scope Medi-Cal coverage for this group includes doctor visits and preventive care, hospital and emergency services, prescription drugs, mental health and substance use disorder treatment, vision care, immunizations, and reproductive health services.
- » **If you are part of this group and do not pay your premium**, your coverage will be reduced to emergency and pregnancy-related services.



What You Can Do: Stay Covered!

- » **Keep your [contact information updated](#)** so you don't miss important notices.
- » Watch your mail and **respond to renewal packets** or letters from your health plan or local county office.
- » **Know your renewal date** so you can go online or work with your local county Medi-Cal office to renew your Medi-Cal if you do not receive notifications.
- » **Keep going to the doctor** and other medical appointments.
- » **Visit our [website](#)** and follow our social media channels for updates.

Ask questions if you're unsure:

- » **Contact your local Medi-Cal office.**
- » **Call the Medi-Cal Member Help Line at (800) 541-5555.**
- » **Contact your health care plan.**



Latino Outreach Program



SEPTEMBER

Friday, September 20th | 6:00–8:00 PM — Redwood City (Sponsor TBD) — Noche de Comunidad: Cena Comunitaria para Familias Latinas. *El Grullense Grill and Seafood.*

Thursday, September 25th | 6:00–8:00 PM — Fresno, CA (Genentech) — Noche de Comunidad: Cena Comunitaria para Familias Latinas. *Sal's Mexican Restaurant.*

NOVEMBER

Friday, November 7th | 6:00–8:00 PM — Santa Rosa (Sponsor TBD) — Noche de Comunidad: Cena Comunitaria para Familias Latinas. Restaurant Location TBD.

Friday, November 14th | 6:00–8:00 PM — Concord, CA (Sanofi) — Noche de Comunidad: Cena Comunitaria para Familias Latinas. Restaurant Location TBD.

Friday, November 21st | 6:00–8:00 PM — Soledad, CA (Sponsor TBD) — Noche de Comunidad: Cena Comunitaria para Familias Latinas. Restaurant Location TBD.



Camper Voice

Alijah Bounkhoun-Em



I had a lot of fun at Camp Hemotion! From the very first day, I met people who have the same condition as me, and it made me realize that I wasn't alone. Spending time with them—laughing, talking, and sharing experiences—helped me feel connected in a way I never had before. It was comforting to hear their stories and know they understood exactly what I go through, without me having to explain every little detail. I learned so much just from being around them, and I felt encouraged to open up about my own experiences. Now, I feel more comfortable with having Hemophilia A because I know there are others walking the same path, facing the same challenges, and celebrating the same victories. Camp gave me a place where I could be myself, where my condition didn't define me, and where friendships were built on understanding and acceptance. It's an experience I'll never forget and I'm grateful for the people I met and the confidence I've gained. 🔥



WHAT'S NEXT? YOU DECIDE.

At Genentech, we're committed to supporting the hemophilia A community in ways that go beyond treatment and focus on you as a person. From sharing real stories and experiences from our Patient Ambassadors, to an educational rap anthem for a hemophilia A treatment, to one-on-one support from a team of experts, we're here to help you take on what comes next.

SCAN THE QR CODE TO SEE HOW
GENENTECH AND THE HEMOPHILIA
A COMMUNITY ARE EMBRACING
WHAT'S NEXT, TOGETHER.



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**GENENTECH IN
HEMOPHILIA**

Genentech
A Member of the Roche Group

Camp Hemotion Family Let's Meet at the Walk for Reunion

By Pedro Preciado



To all the incredible campers, counselors, and staff who made Camp Hemotion 2025 one of the most memorable weeks of the year—thank you. The energy, love, and strength you all brought to camp stayed with me long after we said our goodbyes. Now, I want to invite you to carry that same spirit into our next big adventure together.

On Sunday, November 2nd, I hope you'll join us at Heather Farm Park in Walnut Creek for the Unite for Bleeding Disorders Walk—NorCalBDF's largest fundraiser of the year. This event isn't just about walking; it's about community. It's about showing up for one another, celebrating what makes us strong, and continuing to support the programs that matter most—like Camp Hemotion, Family Camp, emergency assistance, advocacy, and so much more.

We'll have a dedicated Camp Hemotion tent so we can reunite, catch up, and bring back the joy we shared at camp. There will be fun activities, breakfast and lunch provided with a \$25 donation per person, and free walk T-shirts for anyone who raises \$25 or more.

I'm asking you to join the official Camp Hemotion team and walk with us. Let's show up as one strong camp family and support the place that brought us all together. Whether you're walking, fundraising, or just coming to hang out, your presence means the world—and helps keep programs like Camp Hemotion going strong for future campers.

I truly believe the magic of Camp Hemotion can live far beyond that one week in summer. Let's show up, together, and make November 2nd just as unforgettable.

Hope to see you there,

Pedro P. 



Red Cards: Know Your Rights



If you are approached by immigration officers, you have rights no matter what your immigration status is.

The [Immigrant Legal Resource Center](#) has put together “Red Cards”, also known as “Know Your Rights” cards, with information on how to protect your rights when encountering U.S. Immigration and Customs Enforcement (ICE) agents. It’s a small but powerful resource that everyone should know about.

The **Red Card** is a simple, wallet-sized card that individuals can carry with them at all times. In the event that someone is approached by Immigration and Customs Enforcement (ICE) or other law enforcement, the card can be silently handed to the officer. It states the person’s **legal right to remain silent**, to **refuse a search**, and to **speak to a lawyer** all of which are protected by the U.S. Constitution.

This card is especially important here in California, where ICE may still conduct operations in public and private spaces, despite the state’s strong sanctuary policies. Knowing your rights and having a way to express them clearly and calmly can make a critical difference in these encounters.

We encourage every individual, family, and community group to:

- **Download or request Red Cards** in your preferred language.
- **Keep them easily accessible**, such as in a wallet or purse.
- **Share them with friends, coworkers, and neighbors** who may not be aware of this resource.

You can access printable Red Cards at this link:

<https://www.waimmigranthealth.org/immigration-action-center/red-card/>

Together, we can ensure that everyone in our community has the tools and information they need to feel safe, informed, and empowered. 🔥

Tarjetas rojas: Conozca sus derechos



Si eres abordado por agentes de inmigración, tienes derechos sin importar tu situación migratoria.

El Centro de Recursos Legales para Inmigrantes ha elaborado unas «Tarjetas rojas», también conocidas como tarjetas «Conoce tus derechos», con información sobre cómo proteger tus derechos cuando te encuentres con agentes del Servicio de Inmigración y Control de Aduanas de Estados Unidos (ICE). Es un recurso pequeño pero poderoso que todos deberían conocer.

La Tarjeta Roja es una tarjeta sencilla, del tamaño de una cartera, que las personas pueden llevar consigo en todo momento. En caso de que alguien sea abordado por el Servicio de Inmigración y Control de Aduanas (ICE) u otras fuerzas del orden, la tarjeta puede entregarse silenciosamente al agente. En ella se indica que la persona tiene derecho legal a permanecer en silencio, negarse a un registro y hablar con un abogado, todos ellos derechos protegidos por la Constitución de los Estados Unidos.

Esta tarjeta es especialmente importante aquí en California, donde el ICE todavía puede llevar a cabo operaciones en espacios públicos y privados, a pesar de las fuertes políticas de santuario del estado. Conocer sus derechos y tener una manera de expresarlos con claridad y con calma puede hacer una diferencia crítica en estos encuentros.

Animamos a cada individuo, familia y grupo comunitario a:

- Descargar o solicitar Tarjetas Rojas en su idioma preferido.
- Mantenerlas fácilmente accesibles, por ejemplo en una cartera o bolso.
- Compartir las con amigos, compañeros de trabajo y vecinos que no conozcan este recurso.

Puede acceder a tarjetas rojas imprimibles en este enlace:

<https://www.waimmigranthealth.org/immigration-action-center/red-card/>

Juntos podemos garantizar que todos los miembros de nuestra comunidad dispongan de las herramientas y la información que necesitan para sentirse seguros, informados y capacitados. 🔥

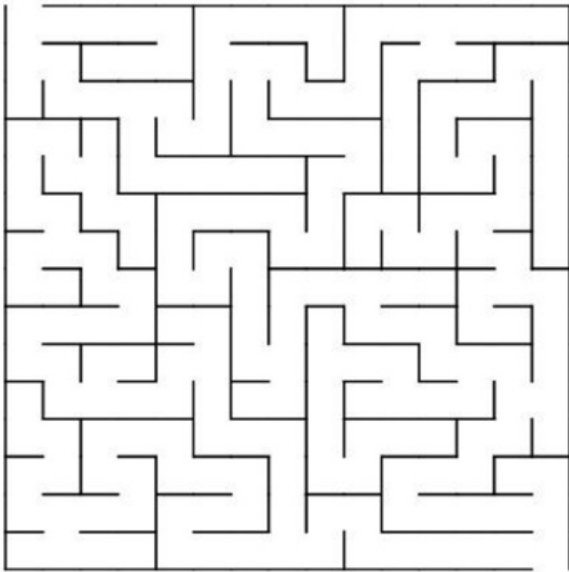


Kid's Page

...and playful adults!



 Start



Spot · the · Difference



Finish



V	R	Y	M	A	G	I	C	W	H
C	A	N	D	Y	F	C	Q	S	S
H	A	L	L	O	W	E	E	N	K
P	W	I	S	P	I	D	E	R	E
U	G	N	C	G	T	L	B	M	L
M	H	P	A	W	C	H	U	O	E
P	O	M	R	P	H	P	C	O	T
K	S	E	Y	O	U	B	A	N	O
I	T	L	L	R	G	A	T	T	N
N	Q	N	I	G	H	T	S	V	O

COLOR ME!

BAT
CANDY
CAT
GHOST

HALLOWEEN
MAGIC
MOON
NIGHT

PUMPKIN
SCARY
SKELETON
SPIDER
WITCH



ALTUVIIIIO®
Antihemophilic Factor (Recombinant),
Fc-VWF-XTEN Fusion Protein-ehtl

Connect with an **ALTUVIIIIO®** Peer Mentor

ALTUVIIIIO Peer Mentors are real patients or caregivers who have had similar experiences to yours.

You'll have the opportunity to:

- Ask questions
- Hear firsthand experiences
- Learn helpful tips
- Get to know others in the community

“ Maybe it's because I've always had such great support, but **engaging with others** is the best way for me to stay happy.

—AJ—

AJ | ALTUVIIIIO patient

AJ is a promotional speaker compensated by Sanofi.



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MAT-US-2406913-v1.0-07/2024

EDUCATION EVENTS

9.21

PACIFIC GROVE

Dinner & Education Hemgenix gene therapy for Hemophilia B
by CSL Behring

10.16

CARMEL

Dinner & Education
by Bayer (topic to be determined)

11.16

FRESNO

Dinner & Education Hemgenix gene therapy for Hemophilia B
by CSL Behring

12.6

WINTERFEST SAN JOSE

12.7

WINTERFEST FRESNO



Carline Hanchett

Regional Account Manager
Serves Southern CA, AZ, HI, NV and UT

Carline has years of experience in healthcare, precision medicine and oncology, which has prepared her well to support the many challenges our patients face. Carline is ready to work tirelessly to enhance patient care through collaboration helping those suffering with rare bleeding disorders.

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CALENDAR

SEPTEMBER 2025

9/1/25	Labor Day	Holiday NorCalBDF closed
9/5/25 -9/7/25	Familia de Sangre	Anaheim
9/13/25	The Female Factor Meets	South San Francisco
9/20/25	Board Meeting	Virtual
9/20/25	Dinner & Dialogue (Spanish)	Palo Alto
9/21/25	Dinner & Education	Pacific Grove
9/26/25	Dinner & Dialogue (Spanish)	Fresno

OCTOBER 2025

10/14/25	Board Meeting	Virtual
10/16/25	Dinner & Education	Carmel
10/24/25	Dinner & Dialogue (Spanish)	Soledad
10/25/25	The Female Factor Meets	Union City
10/26/25	Hemlibra - Dinner & Dialogue (Spanish)	Fresno

NOVEMBER 2025

11/2/25	Unite for Bleeding Disorders Walk	Walnut Creek
11/13/25	The Female Factor Meets (Spanish)	Salinas
11/14/25	Dinner & Dialogue (Spanish)	Concord
11/16/25	Dinner & Education	Fresno
11/17/25-11/20/25	NBDF Chapter Leadership	Charlotte, NC
11/18/25	Board Meeting	Virtual
11/27/25-11/28/25	Thanksgiving Holiday	Holiday NorCalBDF closed

DECEMBER 2025

12/1/25	World AIDS Day	AIDS Memorial Golden Gate Park San Francisco
12/2/25	Giving Tuesday	Campaign
12/6/25	WinterFest	San Jose
12/7/25	WinterFest	Fresno
12/24/25-1/2/26	Winter Break	Holiday NorCalBDF closed

JANUARY 2026

1/1/2026	New Year's Day	Holiday NorCalBDF closed
1/5/2026	New Year's Day	Holiday NorCalBDF reopens

NorCalBDF Northern California Bleeding Disorders Foundation
<https://www.NorCalBDF.org>

AFFILIATED ORGANIZATIONS

BDCC Bleeding Disorders 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://KaiserOaklandPediatricHematology/Oncology>

Jack Russek OMS-II

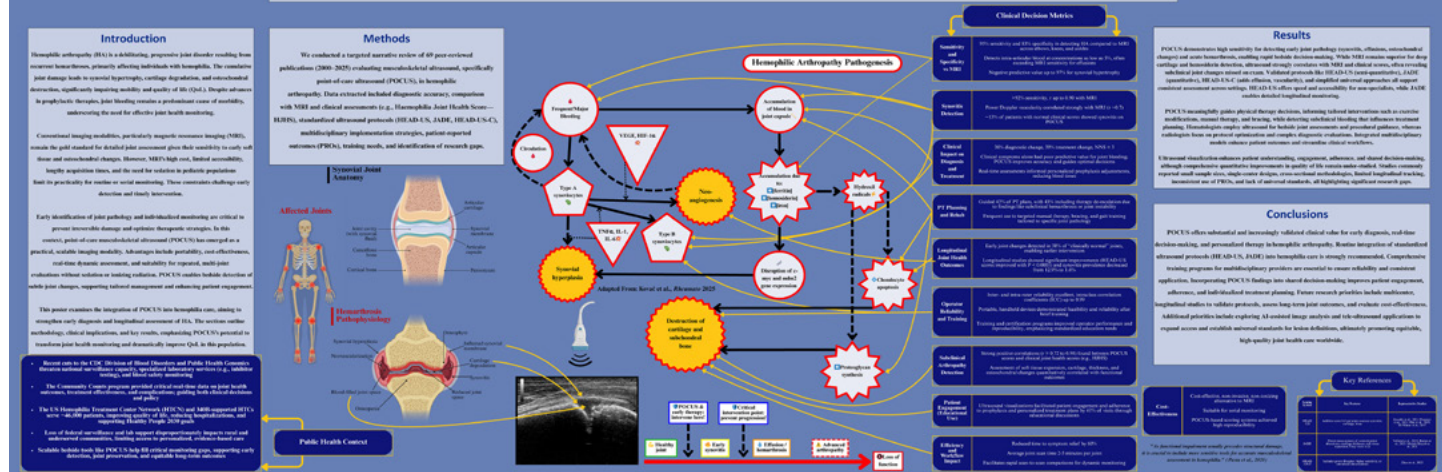
This year, we're proud to share that two of our own community members presented posters at BDC! Please see them here.

Point-of-Care Musculoskeletal Ultrasound in Hemophilic Arthropathy: Evidence Synthesis, Clinical Impact, and Recommendations for Multidisciplinary Implementation

PTI

Jack Russek OMS-II

77th Bleeding Disorder Conference - Aurora, Colorado - August 21 - 23, 2025



Patient-Reported and Clinical Outcomes in People with Hemophilia (PwH) Treated at Federally Sponsored Hemophilia Treatment Centers (HTCs) vs. Non-HTC Clinics: Interim Analysis from the CHES US Study

Authors: Enrico Ferri Grazzi¹, Nicole Crook², Ming Y. Lim³, Adam Giermasz⁴, Jonathan C. Roberts^{5,6}, Maria Santaella⁷, Michael Recht^{7,8}, Randall Curtis⁹

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OBJECTIVE: The objective of this analysis was to compare key clinical, economic and burden of illness outcomes and Patient-Reported Outcomes in PwH in the US who are treated within the US-HTC and those treated at non-HTC clinics, using interim data from the ongoing CHES US longitudinal study.

CONCLUSION: These findings highlight significant disparities between HTCs and non-HTCs. Non-HTC PwH experienced higher overall burden, higher bleeding-related joint morbidity and joint pain, reduced access and adherence to treatment, higher daily living impairment and mental health impact, and lower overall quality of life. These results demonstrate the critical importance of US-HTC and the benefits of highly specialized care.

BACKGROUND

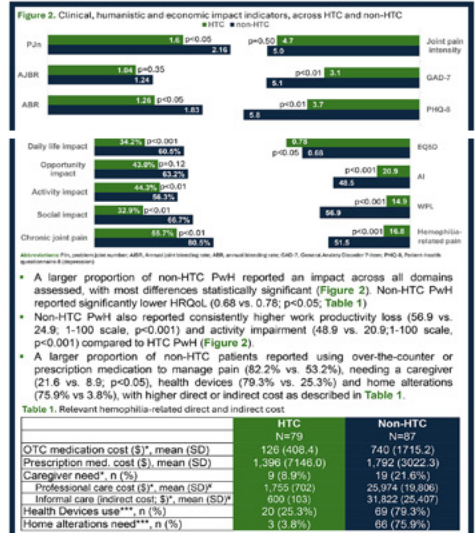
- In the United States (US), hemophilia care is typically delivered by hemophilia treatment centers (HTCs) affiliated with the federally-sponsored Hemophilia Treatment Center Network (US-HTCN).
- However, it is estimated that as many as 30% of people with hemophilia in the US receive their care outside of specialized multidisciplinary HTCs.^{1,2} A proportion of these non-HTC PwH are seen in closed networks (e.g., Kaiser), but the majority are seen in independent non-HTC clinics, not affiliated with any network.
- While the comprehensive care model of HTCs is well established, there is limited information on the quality of life and overall burden of illness between PwH managed in these different care settings.
- Identifying disparities and understanding unmet need is crucial for ensuring equitable access to care for all PwH.
- CHES US aims to assess the socio-economic burden of hemophilia in adult male patients of all severities in the United States of America.

METHODS

- CHES US is a 12-month-retrospective longitudinal burden of illness study, enrolling adult (>18 years) PwH A or B of any severity, with or without inhibitors, living in the US.
- Baseline characteristics, demographics, clinical outcomes, treatment information and health-resource utilization (including hospitalizations, joint procedures and visits) is abstracted into a clinical report form by treating Health Care Providers at independent clinics and federally-sponsored HTCs.
- Clinical outcomes collected include annual (joint and spontaneous) bleeding rates (ABR, AJBR, ASBR), chronic pain intensity and location information, joint health via problem joint, target joint and Hemophilia Joint Health Score.
- Patient-reported outcomes (PROs), health-related quality of life (HRQoL), mental health (via GAD-7 for anxiety and PHQ-9 for depression), work productivity and activity impairment (WPAI) and humanistic impact were reported by enrolled PwH.
- This interim analysis focused on interim data collected in 74 independent clinics and 5 federally-sponsored HTCs, and specifically on the subsample of PwH who had complete information on patient-reported outcomes, and HRQoL.
- Results are presented as means (standard deviation; SD) and frequency (percentage), where appropriate. Data are presented by HTC/non-HTC.
- Statistical significance testing for subgroup comparison was performed via one-way analysis of variance (ANOVA) for continuous variables, and chi-square tests for categorical variables. Results were deemed statistically significant at p-values < 0.05.

RESULTS

- Of the 825 PwH who participated in the study, a total of 166 met the inclusion criteria, n=87 (52.4%) treated in independent clinics and n=79 (47.6%) treated within the US-HTCN network.
- The non-HTC PwH were younger compared to HTC counterparts (30.8 [12.5] vs. 34.6 [13.0]; p<0.05). Hemophilia type distributions were similar, however a higher proportion of PwH in HTCs were severe (n=46; 58.2%), compared with non-HTCs (n=35; 40.2%; p=0.05). Conversely, a much larger proportion were moderate in non-HTCs (48.3% vs. 20.3%; p<0.001) (Figure 1).
- Figure 1. Severity and treatment distribution across HTC and non-HTC
- HTC PwH reported better clinical outcomes overall: with significantly lower ABR (1.3 vs. 1.8) and numerically lower AJBR, better joint health with fewer problem joints (1.6 vs. 2.1) and lower prevalence of chronic joint pain (55.7% vs. 60.4%; p<0.01) (Figure 2). Overall hemophilia-related pain, was significantly lower in HTC patients (16.8 vs. 51.5; 1-100 VAS scale) (Figure 2). Non-HTC patients reported increased mental health impact, both in terms of anxiety (GAD-7, 5.1 vs. 3.1) and depression (PHQ-9, 5.8 vs. 3.1) (Figure 2).



References: 1. Iorio, A. Stonebraker, J., Brooker, M., Soucie, M. Hemophilia (2017), 23, e1-e7. 2. Hemostasis and Thrombosis Data Set (2024). [Unpublished data]. United States Hemophilia Treatment Center Network. 3. Burke, T. et al. Hemophilia 20, 608-618 (2023).

Acknowledgements: The CHES-US study was supported by an unrestricted research grant from BioMarin and governed by an expert review committee chaired by Mr. Randall Curtis.



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