

Infusions

COMMUNITY SPOTLIGHT

Mi Voz Tiene Poder Community Member Thalia Santiago

Mi nombre es Thalia Santiago, y mi historia en este camino de los desórdenes sanguíneos comenzó hace 14 años con mi hijo mayor. Fue entonces cuando descubrí esta hermosa comunidad a través de una invitación a una conferencia enorme llamada Familia de Sangre. Desde ese día, mi vida dio un giro inesperado pero lleno de esperanza. Comencé a conocer a personas maravillosas que me han ayudado a entender y comprender que, con la información adecuada, todo sería mucho más llevadero.


Empecé a asistir a eventos, a participar activamente y a esforzarme por aprender más acerca de la hemofilia B severa, que es el diagnóstico de mis tres hijos varones. Este proceso no ha sido fácil, pero ha sido enriquecedor. Con el tiempo, mi familia y yo hemos adquirido herramientas valiosas que nos han ayudado en muchos aspectos: como personas, como familia y también en términos médicos. Pero sobre todo, hemos aprendido que podemos abogar por otras personas que también lo necesitan.

Amo luchar para que más gente se informe, para que descubran que, cuando estás en los lugares adecuados y rodeado de las personas correctas, el camino se vuelve más fácil de transitar. A lo largo de los años, hemos enfrentado situaciones extremadamente difíciles, momentos de incertidumbre y angustia, pero siempre con la certeza de que no estamos solos como familia.

Lo más hermoso de formar parte de esta comunidad es saber que mi voz tiene poder, que puede marcar una diferencia. Hoy en día, mi esposo, mis hijos y yo trabajamos juntos con el corazón lleno de entusiasmo y determinación para que más personas sepan que esta comunidad está aquí para ayudarles, para acompañarlos y para recordarles que no están solos.

Espero conectarme con todos en el futuro porque el camino sigue siendo brillante y lleno de esperanza. Sigamos avanzando juntos, apoyándonos y aprendiendo unos de otros.

Con cariño y gratitud,

Thalia Santiago 



IN THIS ISSUE



CANNABIS FOR
PHYSICAL PAIN

Page 9



COREY DUBIN
WORLD AIDS
DAY 12/1

Page 12



CAMP
HEMOTION

Page 14



KID'S PAGE

Page 16

Mi Voz Tiene Poder

Community Member Thalia Santiago

My name is Thalia Santiago, and my story on this journey of blood disorders began 14 years ago with my oldest son. It was then that I discovered this beautiful community through an invitation to a huge conference called Familia de Sangre. From that day on, my life took an unexpected but hopeful turn. I began to meet wonderful people who have helped me to understand and realize that with the right information, everything would be much more bearable.

I started attending events, becoming active and striving to learn more about severe hemophilia B, which is the diagnosis of my three boys. This process has not been easy, but it has been enriching. Over time, my family and I have acquired valuable tools that have helped us in many ways: as individuals, as a family and also in medical terms. But most of all, we have learned that we can advocate for others who also need it.

I love to fight for more people to be informed, to discover that when you are in the right places and surrounded by the right people, the road becomes easier to travel. Over the years, we have faced extremely difficult situations, moments of uncertainty and anguish, but always with the certainty that we are not alone as a family.

The most beautiful thing about being part of this community is knowing that my voice has power, that I can make a difference. Today, my husband, my children and I work together with a heart full of enthusiasm and determination to let more people know that this community is here to help them, to accompany them and to remind them that they are not alone.

I look forward to connecting with everyone in the future because the path remains bright and full of hope. Let's keep moving forward together, supporting and learning from each other.

With love and gratitude,

Thalía Santiago 





UNITE FOR BLEEDING DISORDERS WALK 2024



Unite
for Bleeding Disorders

THANK YOU!!



Walkers, Donors, Volunteers, Sponsors



Women and girls
affected
and
connected
to
bleeding disorders

Join Us for

THE *Female Factor* RETREAT



THE FEMALE FACTOR
Affected and connected

Gather 'round the crackling flames, sip on warm drinks, and revel in the enchanting atmosphere. It's an event to remember, filled with education, workshops, guided activities, laughter, camaraderie, and the cozy glow of a roaring bonfire. Ages 13+ (minors must be accompanied by adult)

CHECK IN THURSDAY FEB 6 2025
CHECK OUT SUNDAY FEB 9 2025

Villa Maria Del Mar 21918 E Cliff Drive Santa Cruz CA 95062



SCAN ME



The
Hemophilia
Foundation of
Northern California

FOR ALL BLEEDING DISORDERS

Register

hemofoundation.org/events

Contact

ashley.gregory@hemofoundation.org

510-658-3324



Pedro Preciado

Una Actualización Importante para Todos Mis Amigos y Familia Dentro de la Comunidad de Trastornos de Sangrado

Mi Querida Familia,

Espero que esta carta los encuentre a ustedes y a sus familias excepcionalmente bendecidos, prósperos y saludables. Siento que ha pasado demasiado tiempo desde la última vez que tuve la oportunidad de dirigirme a esta maravillosa comunidad. Estoy profundamente agradecido con el equipo de la Fundación de Hemofilia del Norte de California por invitarme a compartir algunas emocionantes novedades.

Para quienes aún no he tenido el placer de conocer, mi nombre es Pedro Daniel Preciado. Soy hijo de padres inmigrantes mexicanos trabajadores, recientemente graduado con una licenciatura en Psicología de la Universidad Estatal de California, East Bay, y orgulloso miembro de la comunidad de trastornos de sangrado, viviendo con Hemofilia A Moderada. Desde 2022 hasta 2023, serví como Coordinador de Alcance Comunitario y Participación para la Fundación de Hemofilia, ayudando a planificar y organizar eventos increíbles como la Caminata UNITE por los Trastornos de Sangrado, Camp Hemotion, Winterfest y diversos programas educativos y cenas.

¡Los he extrañado muchísimo! Con esta carta, quiero explicar mi ausencia y compartir las aventuras que he vivido durante este tiempo. Compartir comidas, crear lazos y conectar a través de nuestras experiencias con los trastornos de sangrado rápidamente se convirtió en lo más destacado de mi rol. Al final de mi tiempo con la Fundación, sabía que esos recuerdos fortalecerían mi determinación de mantenerme activo en la comunidad, incluso mientras me alejaba para enfrentar nuevos desafíos.

Esta decisión surgió de un deseo personal de salir de mi zona de confort y dar un salto de fe hacia territorios desconocidos. Me mudé con un familiar cercano a quien admiro profundamente, alguien que me retó a mantener altos estándares, poniendo a prueba mi independencia y resiliencia. Esta experiencia me permitió reflexionar profundamente sobre mi camino, realinear mi misión y fortalecer mi fe, tal como muchos en nuestra comunidad lo hacen cada día.

Después de un año fuera, un mes apoyando al equipo de Camp Hemotion y muchas conversaciones significativas con amigos y colegas, estoy emocionado de anunciar mi regreso a la Fundación de Hemofilia del Norte de California como su Coordinador de Alcance y Participación. Estoy feliz de estar de vuelta y emocionado de trabajar junto a nuestra inspiradora nueva Directora Ejecutiva, April Streger, cuya visión está dando forma a un futuro emocionante para 2025, y nuestra comprometida Directora Asociada, Ashley Gregory, cuya experiencia y dedicación continúan fortaleciendo nuestra misión de brindar cuidado y apoyo a todos.

Estoy entusiasmado con el futuro mientras trabajamos juntos para construir una comunidad tan fuerte que incluso los miembros más aislados sientan el cálido abrazo de esta familia, tal como ustedes lo hicieron por mí cuando descubrí lo que deparaba el futuro como un miembro recién diagnosticado de la comunidad. Todos ustedes son parte de mi familia, y espero con ansias volver a ver sus caras sonrientes muy pronto mientras compartimos comidas, creamos lazos y nos reconectamos, tal como lo hace una familia.

Cúdense mucho, y nos veremos muy, muy pronto.

Con cariño y gratitud,

Pedro D. Preciado

Coordinador de Alcance y Participación de HFNC

Si deseas mantenerte conectado y seguir mi camino, puedes encontrarnos como @hemo_norcal en Instagram, "The Hemophilia Foundation of Northern California" en Facebook, o visitar nuestro sitio web en www.hemofoundation.org/events. Estaré compartiendo contenido emocionante y atractivo para mantenerte informado sobre nuestros próximos eventos. Juntos, traeremos de vuelta la "Fiesta" a la Fundación y haremos de 2025 un año inolvidable. ¡Espero verte allí! 🔥



Pedro Preciado

An Important Update for All My Friends and Family Within the Bleeding Disorders Community

Mi Querido Familia, I hope this letter finds you and your family exceptionally blessed, prosperous, and healthy. It feels like it's been far too long since I last had the opportunity to address this wonderful community. I'm deeply thankful to the team at the Hemophilia Foundation of Northern California for inviting me to share some exciting new developments!

For those I haven't had the pleasure of meeting yet, my name is Pedro Daniel Preciado. I am the son of hardworking Mexican immigrant parents, a recent Bachelor's degree graduate with a focus in Psychology from California State University, East Bay, and a proud member of the bleeding disorders community, living with Moderate Hemophilia A. From 2022 to 2023, I served as the Community Outreach and Engagement Coordinator for the Hemophilia Foundation, helping to plan and host incredible events like the UNITE for Bleeding Disorders Walk, Camp Hemotion, Winterfest, and various other educational programs and dinners.

I've missed you all so much! With this letter, I want to shed light on my absence and share the adventures I've been up to during my time away. Breaking bread, bonding, and connecting through our bleeding disorder journeys quickly became the highlight of my role. By the end of my time with the Foundation, I knew those memories would strengthen my resolve to stay active in the community, even as I stepped away to pursue new challenges.

This decision stemmed from a personal desire to leave my comfort zone and take a leap of faith into uncharted waters. I moved in with a close relative whom I greatly admire, someone who challenged me to hold myself to high standards, testing my independence and resilience. This experience allowed me to reflect deeply on my journey, realign with my mission, and grow stronger in my faith—just as so many in our community do every day.

After a year away, a month supporting the Camp Hemotion team, and many meaningful discussions with friends and colleagues, I'm excited to announce my return to the Hemophilia Foundation of Northern California as your Outreach and Engagement Coordinator. I'm thrilled to be back and excited to work alongside our inspiring new Executive Director, April Streger, whose vision is shaping an exciting future for 2025, and our committed Associate Director, Ashley Gregory, whose expertise and dedication continue to strengthen our mission to provide care and support for everyone. I'm eager for the future as we work together to build a community so strong that even the most isolated members among us feel the warm embrace of this family, just as you did for me when I was first discovering what the future would hold as a newly diagnosed member of the community. You are all part of my familia, and I look forward to seeing your smiling faces again soon as we break bread, bond, and reconnect—just like a family should.

Take care, and see you all very, very soon.

Con cariño y gratitud,

Pedro D. Preciado

HFNC Outreach and Engagement Coordinator

¡Si quieres leer mi historia en español, visita nuestro sitio web o escanea este código QR!

If you'd like to stay connected and follow my journey, you can find us @hemo_norcal on Instagram, "The Hemophilia Foundation of Northern California" on Facebook, or visit our website at www.hemofoundation.org/events. I'll be sharing exciting and engaging content to keep you informed about our upcoming events. Together, we'll bring the "Fiesta" back to the Foundation and make 2025 a year to remember. Hope to see you there! 🔥

ADVATE
[Antihemophilic Factor
(Recombinant)]

ADYNOVATE
[Antihemophilic Factor
(Recombinant), PEGylated]

YOUR LIFE IS YOUR CANVAS

Whether it's **ADVATE** or **ADYNOVATE**, look to the **TAKEDA** family to be there with you wherever life takes you.

Keep Painting Your Story

Patient Portrayal



Get access to
Takeda Patient Support



©2024 Takeda Pharmaceuticals U.S.A., Inc., 500 Kendall Street, Cambridge, MA 02142. 1-877-TAKEDA-7 (1-877-825-3327). All rights reserved. TAKEDA®, the TAKEDA Logo® and the Takeda Patient Support logo™ are trademarks or are registered trademarks of Takeda Pharmaceutical Company Limited. ADVATE® and ADYNOVATE® are registered trademarks of Baxalta Incorporated. US-XMP-2841v1.0 08/24





Shelley Jajeh

Your Bleeding Disorder Advocate

Hello,

My name is Shelley Jajeh, and I am your bleeding disorder advocate. I would like to extend a warm welcome to everyone in the bleeding disorder community. I, too, have a bleeding disorder and a son, Matthew, with Severe Hemophilia. As someone who is passionate about helping people manage their bleeding disorder needs, I would love to offer my services to you. I feel fortunate to be a part of a company that shares the same values and principles as I do when it comes to providing excellent patient care. SCR_x is dedicated to putting patients first. It is a privilege to work for an organization that is committed to making a positive impact on the lives of our patients.

At times, navigating the healthcare system and managing your bleeding disorder can be overwhelming, which is why I am here to help. I recognize that patients have the right to choose the healthcare provider that best suits their needs, and I fully respect and support their choice. SCR_x is here to serve and support patients in the best way possible, and we are committed to providing high-quality care that meets their individual needs and preferences. With that said, I would be honored to assist you in managing your care and helping you achieve all your life goals while managing your bleeding disorder.

As your advocate, I will work with you to ensure you have access to the necessary resources and support to manage your bleeding disorder successfully. Whether it's connecting you with healthcare providers, assisting with insurance claims, or providing education materials, I will be with you every step of the way, no matter the circumstances. If you ever want to discuss hemophilia or living with a bleeding disorder, I am here to listen and offer support however I can.

If you are interested in learning more about how I can help you, please contact me at sjajeh@myscrx.com or call/text me at 650.490.0885.

Thank you for considering me as your bleeding disorder advocate.

I won't let you down!

Cannabis for Physical Pain and Mental Health

by Lori Lawler, Community Member

I am writing this article to share my knowledge and experience with the use of cannabis for Physical Pain and Mental Health. I am also writing this to break the stigma around cannabis use. In my opinion there are far to many benefits for people to still be shaming others about their use. I have attended many virtual presentations and lectures provided by doctors with the Society for Cannabis Clinicians, i'm also adding some very basic info with linked sources, so you may dig into this deeper if you like.

My advice is as follows:

1. Disclose to your medical providers and HTC about your cannabis use.
2. Some precautions must be taken regarding other medications you use or may be prescribed. This is especially important when it comes to Anesthesia during medical procedures.
3. Beware of edibles that are homemade as they are hard to dose and too much can have varying side effects. Also just be careful with them in general and start small
4. Seek out compassionate care use dispensaries to help offset the cost of products
5. Only consume products from dispensaries, pharmacies, or trusted sources.
6. THC and CBD consumption for physical pain and mental health
 - a) Topical THC and/or CBD for joint pain, muscle pain, and arthritis
 - b) THC and CBD flower can be smoked to relax anxiety and ease joint pain
 - c) THC and/or CBD oils can be applied topically or vaped for joint pain, or anxiety.
7. Tolerance breaks are a must, every few months take a week off.
8. Dronabinol or Marinol is a prescribed synthetic THC pill taken to boost appetite in those who require an appetite stimulant.
9. Don't buy gas station or cigarette shop CBD products, Always buy from a dispensary and buy a full spectrum CBD product Not Hemp CBD as it is not the same

There is a lack of formal scientific knowledge about cannabis due to its legal status but it has been used as a medicinal plant by people in many different cultures all over the world for thousands of years. The earliest recorded use of cannabis for medicinal purposes was from 2700 b.c. in China.

By about the 8th century, cannabis was used for medicinal purposes in China, Egypt, Greece, India, and the Middle East. In the mid-19th century and early 20th century, cannabis was included in hundreds, if not thousands, of patent medicines, including tinctures, powders, and syrups. They were billed as cures for gout, rheumatism, migraine, cough, asthma, "female problems," pain, sleep problems, and epilepsy.

<https://pmc.ncbi.nlm.nih.gov/articles/PMC5312634/>

Medicinal cannabis products are derived from specific variations or "strains" of the cannabis plant that have been selectively bred to produce over 100 different cannabinoids, the compounds in cannabis that produce medicinal and psychoactive effects. These cannabinoids work by binding to the cb1 and cb2 receptors that are naturally present in our bodies. These receptors are part of our endocannabinoid system, which is responsible for regulating the neurotransmitters that control many of our body functions, including appetite, memory, pain response, sleep, inflammation, and emotional response. 🔥

<https://www.health.harvard.edu/blog/the-endocannabinoid-system-essential-and-mysterious-202108112569>



SCHEDULE ELIGIBILITY TESTING TODAY!

TALK TO YOUR DOCTOR TO GET STARTED.

Learn about the testing needed on [HEMGENIX.COM](https://www.HEMGENIX.COM)



HEMGENIX is manufactured by uniQure Inc. and distributed by CSL Behring LLC. HEMGENIX® is a registered trademark of CSL Behring LLC.

©2024 CSL Behring LLC
1020 First Avenue, PO Box 61501, King of Prussia, PA 19406-0901 USA
www.CSLBehring.com www.HEMGENIX.com USA-HGX-0623-APR24

CSL Behring



Michael Bradley

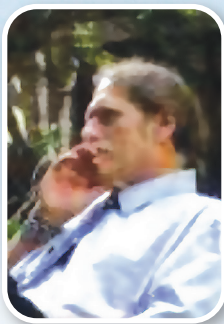
We are thrilled to spotlight **Michael Bradley**, a dedicated member of our community with a longstanding commitment to hemophilia advocacy and support. Mike's journey began in 1986 when he worked in the special hematology lab at Children's Hospital Oakland. Over the years, his career led him to Baxter, where he and HFNC crossed paths many times.

A passionate advocate, Mike has served as president of the Hemophilia Council of California and recently completed a two-year term on our Board of Directors. This year, Mike and his wife made a generous donation to support our upcoming Unite for Bleeding Disorders Walk. We are incredibly grateful for their contribution and for Mike's unwavering dedication to the bleeding disorders community.

Thank you, Mike, for everything you do! 🔥



Corey Dubin: His Actions Equaled Life



Corey Dubin heard my anguish. He would tell me years later that he still remembered that day. I was having a body cast removed after a hip bleed at age 8. My cries of pain echoed down the hospital corridor. Pain and Hemophilia are forever intertwined. That would not be the first time Corey would see or hear the suffering caused by the insidious bleeding disorder. But unlike many of us, Corey also heard something more powerful. He heard his calling.

Corey heard a cry from a community that all too often suffered from this disease. So, Corey stared down his pain from bleeding episodes and refused to blink first. To give in was not an option. With the encouragement of his father, Al Dubin, Corey grew to be a leader in the Southern California Hemophilia community. He would live his life to the fullest and do all the things any young man would do. He showed he was not a Hemophiliac or even worse a hemo- (a word he hated) but a person who also happened to have Hemophilia. As it turned out the leadership skills he acquired while growing up to be a man would be tested later by a far more heinous foe: Acquired Immune Deficiency Syndrome AIDS.

Corey was an accomplished journalist reporting on Latin and US American foreign policy. Corey worked in Central America and later became the director of public affairs for KPFK radio in Los Angeles. This experience honed his sense of social justice for everyone, not just the privileged few. It was one more step to prepare him for the role of his lifetime.

It was in a newsroom one day that his fate came over the teletype. The story had broken that people in the U.S. with Hemophilia who had taken Factor VIII and Factor IX were likely to have contracted HIV/AIDS. In the 1980's that was a death sentence. Corey was always someone who wanted to personify strength. That day, however, he broke down and cried when he read this report. He would subsequently find out that, indeed, he had contracted HIV and like everyone Corey was jolted in a seismic way. But he would not succumb to self-pity. There was no time for that.

As the 1990's began Corey had already begun the "work" to fight the stigma of AIDS. He used the powerful tools of education and leadership. Corey was chair of the Santa Barbara County HIV/AIDS Ryan White Title II Consortia. He was also appointed to the California Community Working Group (CPWG) where he drafted the CA. HIV/AIDS Prevention Plan.

Still, it was in the later part of 1992 when Corey joined the board of the Committee of Ten Thousand (COTT) where he made his biggest impact. COTT began in New England in 1989. The original board of co-founders Tom Fahey, Jonathan Wadleigh and Greg

Haas had started an advocacy organization for those who had Hemophilia and were now infected by HIV/AIDS. Corey joined the Committee of Ten Thousand (so named for the ten thousand people with Hemophilia who were ravaged by AIDS) This organization, would become COTT East and COTT West. In the years to follow Corey Dubin established himself as a true leader within the organization and with the founders. These dedicated people were infected with HIV/AIDS (and in some cases Hepatitis C) and passed away so Corey became president of COTT in 1999. From his arrival at COTT in 1992 Corey distinguished himself by being the first grassroots end user of our nation's blood supply to be appointed to the FDA's Blood Products Advisory Committee (BPAC). He served a second term starting in 2012. Corey was also instrumental in the passage of the Rickey Ray Relief Fund Act of 1999 and worked closely with organizations like the Institute of Science, National Academy of Sciences, etc.

Corey Dubin made it simple. He made it clear that anyone receiving blood or blood products was a canary in the coal mine. Therefore, the blood supply of this country must be protected with the highest integrity of regulatory standards from our government institutions. It was why COTT from its inception would not accept donations from pharmaceutical companies. Corey felt that COTT must always be able to maintain its role as an objective advocate for the Hemophilia community. One important task was to hold government institutions and pharmaceutical companies that manufactured factors accountable. Another important facet was to educate people with Hemophilia and their families to have "Informed Consent" in their medical care.

Some more honors and achievements can be listed for Corey Dubin both in his public and personal life, a personal life that he sacrificed many times for the Hemophilia community. Yet what many of us who knew Corey will always remember are the intangibles: his gift for understanding the science of the holocaust of AIDS, his commitment to be inclusive in his approach to seek justice, including early on when he reached out (when many did not) to Gay men and the Gay community and his ability to listen to someone who was in pain or suffering. Even that day when I was 8 years old and didn't know he was there, he heard me. In the years to come, I believe Corey will always be listening.

Corey leaves a loving and supportive wife, Phoebe (Faviana) Hirsch Dubin, with three children and six grandchildren. In 2016 The National AIDS Memorial Grove in conjunction with several Hemophilia organizations agreed to create a Memorial for people with Hemophilia who died from HIV/AIDS and/or Hepatitis C. Having a memorial for those who died from AIDS with hemophilia and for their families and friends was something very important to Corey. With his passing the success of the memorial project holds even greater meaning today. 🔥

HIV/AIDS Sunday, December 1 is World AIDS Day

Author Jeffrey Moulalim, Community Member



About the Author: Jeffrey was born in 1955 with severe Hemophilia A. He was the first person in his family to have Hemophilia. It took a few months before he was diagnosed correctly, but the disease was already affecting his joints. For the first 12 years whole plasma or blood transfusions were the only way to help stop a bleeding episode. These methods were average at best.

At 12 years old Factor VIII concentrate became available. This changed the course of hemophilia treatment and allowed much more physical activity. Unfortunately, what seemed like a godsend turned into a death sentence for many in the Hemophilia community in the 1980s.

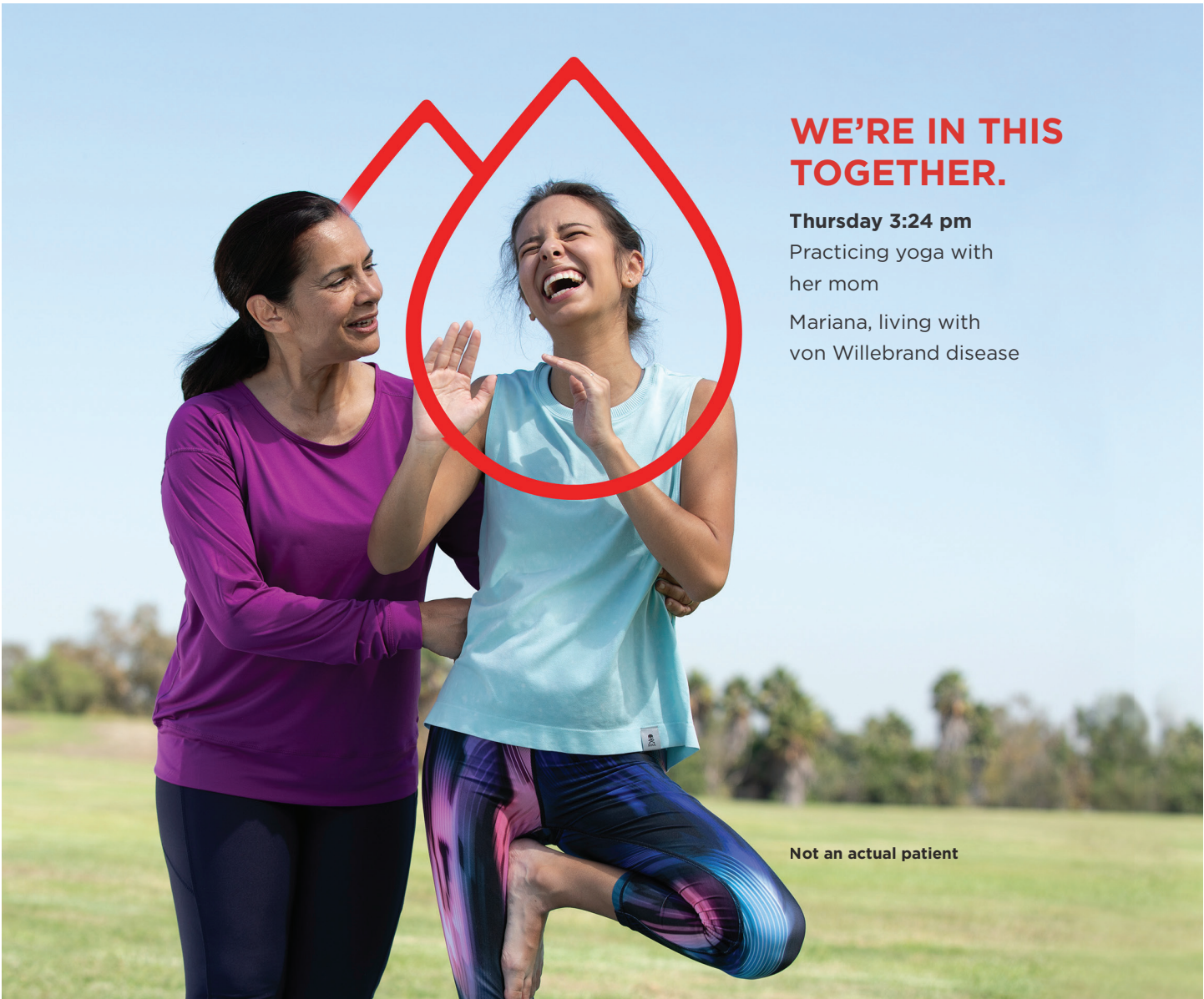
Although Jeffrey was able to avoid HIV/AIDS he contracted Hepatitis C. In 2005 his liver went into complete liver failure. The day after Christmas that year Jeffrey was saved with a liver transplant at UCLA.

After a long recovery, Jeffrey joined the Committee of Ten Thousand Board (COTT) in 2007. He served for 8 years until the summer of 2015. It was at that point that Jeffrey set out to accomplish one of COTT's prime objectives. A Memorial for all those who perished who had hemophilia and contracted AIDS. Working closely With the National AIDS Memorial Grove in San Francisco CA by 2017 there was the unveiling of a Hemophilia Memorial At the Grove.

In the last 7 years, Jeffrey has continued to advocate in the Hemophilia Community. Jeffrey has been married for 33 years to his wife Sue. Now living in Tehachapi CA with their 3 rambunctious dogs! 🔥



At the AIDS Memorial Grove in S.F
with Jeannie White Ginder
(Ryan White's Mother)



WE'RE IN THIS TOGETHER.

Thursday 3:24 pm
Practicing yoga with her mom
Mariana, living with von Willebrand disease

Not an actual patient

Let's make today brilliant.

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to adult patients with von Willebrand disease is stronger than ever.

*Not all activities are appropriate for all individuals.
Consult your doctor prior to engaging in any activity.*

 | 

Copyright © 2020 Takeda Pharmaceutical Company Limited. All rights reserved. TAKEDA and the TAKEDA logo are trademarks or registered trademarks of Takeda Pharmaceutical Company Limited. US-NON-1141v1.0 06/20

Camp Hemotion

by Scarlett Peepe, Camp Alumni

My experience at Camp Hemotion has given me opportunities that I never would have gotten outside of camp and gave me lifelong friendships that I will forever be grateful for. I first stepped foot onto Camp Oakhurt's grounds as an enthusiastic eight year old ready to explore, meet new friends and have fun for a week. This year I got to leave after being a junior counselor for the first time with friends I made back in my first summer when we were only eight years old. I've seen friends, counselors, directors and staff come and go but every time I arrive it always feels like home.

Throughout my years as a camper I got to participate in many activities that I would have never gotten to experience at school without the support of a medical staff that is trained to deal with bleeding disorders; these activities include gaga, basketball, volleyball, etc, and of course some activities you can only experience at camp like a high ropes course, rock climbing, archery and the giant swing. An amazing aspect of camp is not only getting to participate in these events but to feel safe and supported while doing them.

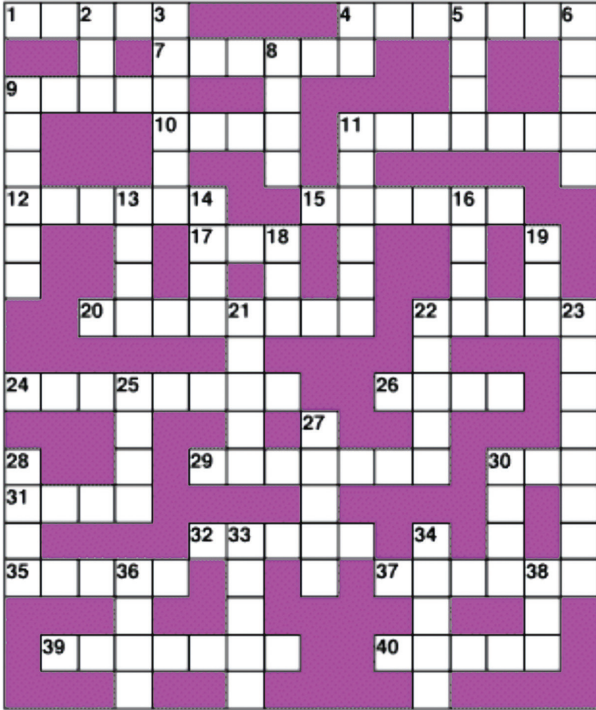
The young campers always looked up to the older campers and counselors when they were younger, never thinking they would ever grow up and do what they do, but we did. This past summer I got the joy of being a junior counselor for the first time. I made such amazing connections with the girls in my cabin and felt so fulfilled to be able to give them the same adventures that I got to have as a camper. We also got the unique experience of having a service dog in our cabin who the girls loved to help feed and play with. One of the best parts was working together with the other junior counselors to make the best experience for our campers, we spent hours working on a carnival and dressing up to make sure they got the best experience possible. It was one of the most rewarding things I've ever done. 🔥





Kid's Page

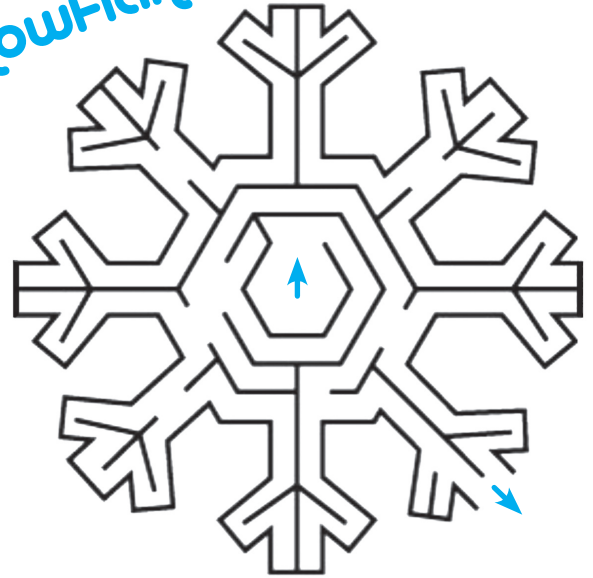
...and playful adults!



Down:

2. Frozen water
3. Small
4. Myself
5. Small pie
6. Neck warmer
8. Chilly
9. Used to move snow
11. A season
13. Strong emotion
14. Ripped
16. Nil
18. Bath _____
19. Cloud of water vapour
21. Last month of winter
22. Wooden snow vehicles
23. Winter road condition
25. Be carried on
27. Locomotive
28. Carried along by wind
30. Piece of hockey equipment
33. Make this in the snow
34. Winter foot wear
36. Faucets can do this
38. You hear with this

Snowflake Maze



Across:

- | | |
|-----------------------------|-------------------------------|
| 1. Sudden cold breeze | 24. Valentine month |
| 4. Hand warmers | 26. Thaw |
| 7. Hanging spike of ice | 29. Keeps drinks warm |
| 9. Freezing rain | 30. Small dog |
| 10. Show and _____ | 31. Winter Olympic sport |
| 11. Conditions outside | 32. Silky material |
| 12. Flowering plant, colour | 35. Breezy |
| 15. Achoo | 37. Ice sport |
| 17. Not in | 39. Foot warmer |
| 20. Month of winter | 40. Direct a vehicle's course |
| 22. Carols, etc. | |

It's snow joke....



What do snowmen eat for lunch?

Snowbergers!

Where does a Yeti surf the internet?

On the winter-net

What did the icy road say to the car?

Wanna go for a spin!

What do you call a polar bear with no ears?

anything you want!



Word search puzzle

candle
cookie
garland
reindeer
Santa Claus
snowman
sweater
winter
wonderland
Yule

W	O	N	D	E	R	L	A	N	D	U	G
G	J	X	F	O	U	J	X	F	J	G	A
S	O	R	E	I	N	D	E	E	R	X	R
A	X	J	O	G	G	J	X	F	O	U	L
N	F	W	X	C	O	C	J	G	S	O	A
T	X	I	J	A	J	O	O	X	W	F	N
A	J	N	G	N	X	O	G	U	E	J	D
C	O	T	J	D	F	K	J	O	A	G	X
L	G	E	X	L	J	I	X	J	T	O	Y
A	J	R	G	E	O	E	O	G	E	X	U
U	O	G	J	X	F	O	U	J	R	J	L
S	X	S	N	O	W	M	A	N	X	O	E

CALENDAR

DECEMBER

12/1/24	World AIDS Day	AIDS Memorial Golden Gate Park San Francisco, CA
12/3/24	Giving Tuesday	Campaign
12/7/24	WinterFest	San Jose
12/15/24	WinterFest	Fresno
12/24/24	Christmas Eve	Holiday HFNC closed
12/25/24	Christmas Day	Holiday HFNC closed
12/23/24-1/1/25	HFNC Office Closed	Holiday HFNC closed

JANUARY 2025

1/1/25	New Year's Day	Holiday HFNC closed
1/14/25	Board of Director's Meeting	In Person
1/20/25	MLK Jr Day	Holiday HFNC closed

FEBRUARY 2025

2/6/25-2/9/25	The Female Factor Retreat	Villa Maria del Mar Santa Cruz
2/11/25	Board of Director's Meeting	Virtual
2/17/25	President's Day	Holiday HFNC closed
2/20/25-2/23/25	YETI Conference	Camp Collins, OR
2/28/25	Rare Disease Day	TBD

MARCH

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

APRIL 2025

4/4/25-4/6/25	Western States Region IX Conference	Ko'olina, Hawai'i
4/8/25	Board Meeting	Virtual
4/17/25	World Hemophilia Day	Small, regional and digital.
4/20/25	Easter	Holiday HFNC closed

MAY 2025

5/4/25	SpringFest/Family Education Event (includes Emerging Therapies, Advocacy)	Six Flags Tickets, Safari west
5/13/25	Board Meeting	In Person, San Francisco, CA
5/26/25	Memorial Day	Holiday HFNC closed

JUNE 2025

6/10/25	Board Meeting	Virtual
6/21/25-6/28/25	Camp Hemotion	Camp Oakhurst, Coarsegold, CA

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

AFFILIATED ORGANIZATIONS

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

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

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

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

HEMOPHILIA TREATMENT CENTERS (HTC's)

Stanford University Medical Center
<https://www.stanfordchildrens.org/en/service/hematology>

UCSF Benioff Children's Hospital Oakland
<https://www.childrenshospitaloakland.org>

University of California at Davis
<https://www.ucdmc.ucdavis.edu/hemophilia/>

University of California San Francisco
https://www.ucsfhealth.org/clinics/hemophiliatreatment_center/

Valley Children's Hospital
<https://www.valleychildrens.org/>



The
Hemophilia
Foundation of
Northern California

FOR ALL BLEEDING DISORDERS

END OF YEAR
2024

COMMUNITY REPORT



199

**NEW
COMMUNITY
MEMBERS**



34

**ACCESSED
ADVOCACY DEPARTMENT**

143

**WELCOME
KITS SENT**

HEMOFOUNDATION.ORG



The
Hemophilia
 Foundation of
 Northern California

FOR ALL BLEEDING DISORDERS

INFORME DE APOYO
 2024

**COMUNITARIO
 DE FIN DE
 AÑOEAR**



199

COMMUNIDADES
 NUEVOS
 MEMBROS



34

ACCEDIDO
 APOYO DE PROMOCIÓN

143

BIENVENIDO
 PAQUETES ENVIADOS

HEMOFOUNDATION.ORG

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.



The Genentech logo is a registered trademark of Genentech, Inc.
©2024 Genentech USA, Inc. All rights reserved. M-US-00008064(v2.0) 06/24

**GENENTECH IN
HEMOPHILIA**

Genentech
A Member of the Roche Group



Pfizer is changing the hemophilia B treatment landscape.

Backed by over 25 years
of commitment to the
hemophilia community.

Learn more at
yourbleedprotection.com.

PP-BEQ-USA-0321 © 2024 All right reserved. July 2024



Hemophilia Foundation of Northern California
1155-C Arnold Drive #236
Martinez CA 94553



The Hemophilia Foundation of Northern California (HFNC) 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 HFNC, 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 Hemophilia Foundation of Northern California, or those of the editorial staff.

MATERIAL PRINTED IN THIS PUBLICATION MAY BE REPRINTED WITH THE EXPRESS PRIOR WRITTEN PERMISSION FROM THE EXECUTIVE DIRECTOR. SPRING, SUMMER, FALL OR WINTER WITH YEAR MUST BE INCLUDED.

Hemophilia Foundation of Northern California is a 501(c)(3) non-profit. Donations are tax-deductible, much needed and appreciated.

BOARD OF DIRECTORS

Randy Curtis
BOARD PRESIDENT

Dawn Pollard
VICE PRESIDENT

Derek Sim
SECRETARY

Anita Bawa
TREASURER

Kerri Borgese, BSN,
RN, IBCLC

Michael Bradley
Leslie Ferber

Mark Helm

Elaine Lai

Tiffany Lucas, MD

Mosi Williams

BOARD MEMBERS

STAFF

April Steger
EXECUTIVE DIRECTOR

Ashley Gregory
ASSOCIATE DIRECTOR

Pedro Preciado
OUTREACH & ENGAGEMENT
COORDINATOR BILINGUAL

CONTACT INFORMATION

1155-C Arnold Drive #236
Martinez CA 94553

Office hours: Mon-Fri, 9am-5pm

www.hemofoundation.org
infohfnc@hemofoundation.org

(510) 658-3324 phone
(510) 658-3384 fax



is published four times per year by Hemophilia Foundation of Northern California

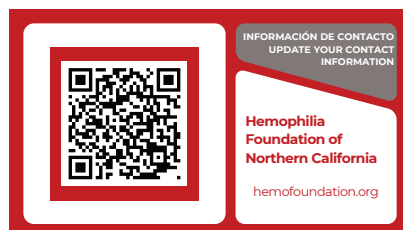
Editor Ashley Gregory, Associate Director

Medical Editor Tiffany Lucas MD, Medical Director

Contributors Shelley Jajeh, April Steger, Pedro Preciado

IN 2025 INFUSIONS WILL BE PUBLISHED FOUR TIMES PER YEAR:

- MARCH 1 (ONLINE)
- JUNE 1 (ONLINE)
- SEPTEMBER 1 (ONLINE)
- DECEMBER 1 (ONLINE AND PRINT VERSION MAILED)



Visit our website at www.hemofoundation.org for important information.

If you would like to advertise in the next issue, please contact us at ashley.gregory@hemofoundation.org

Want to update your contact information?

Go [HERE](#)

Scan the QR code

Call/text 510-658-3324

[email to ashley.gregory@hemofoundation.org](mailto:ashley.gregory@hemofoundation.org)