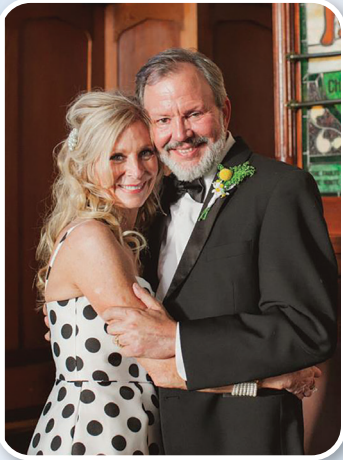


# Infusions



## Bob Seaton in Memoriam

By Tara Gormaly Stauber (with permission)

**We lost another incredible soul from our lives. Life can change in a minute.** My sweet brother-in-law, Bob, died from a hemorrhage due to hypertension causing a severe brain bleed. Here is my story of my dynamic, funny, and passionate brother-in-law, Bob....

Once upon a time, there was a guy named Bob, Uncle Bob, Bobby, Robert, Senator Seaton, BBQ Bob, one-eyed captain, Mr. First in line at every buffet, and most notably, the Guitar man, ...

He was born with a rare blood disorder, hemophilia, at a time when the condition was not understood very well. He outlived all the odds placed against him!! The doctors told his parents they could either put him in a bubble or let him live like a normal kid but he would not likely live long-- but he'll be happy. So they let him live. 70 years later and our favorite guitar man has only now left the studio to join his favorite musicians in the sky.

He lived a life better than most anyone we know. He never let the idea of his condition get in the way of the life he wanted to live and the things he wanted to do. He was quite remarkable in this way, actually in so many ways. He brought a smile to every gathering despite the aches and pains that came with a long life of internal bleeds. He reminded us all of how attitude and laughter can affect the quality of your life in the best of ways.

Above all, Bob was a family man. His devotion and dedication to his lovely wife, Lynn (of almost 50 years!), and two girls was undeniable. He adored them all .... and then there are the grandchildren! The lights of his life. He was so happy and content in this family world.

We counted on Mr. First in line at every buffet to kick off our family meals. He had the digestion of a crocodile, he could

eat more than people twice his size and not gain an ounce. He baffled us all! (And made some of us quite jealous--yes, that would be me.) Buffets will never be the same without him.


His passion for music was contagious and exceptionally fun. We loved it when Bob showed up with his guitar. He had a very extensive repertoire of music favorites, but perhaps at the top of his list was the Beatles. If it was your birthday you were likely to get a call from him singing 'they say it's your birthday da da na na na na na. We're gonna have a good time which was also a highlight to all our birthday celebrations.

He could find a song for any situation. He played despite the pain in his elbows from years of internal bleeding that ruined the joints. Besides his family, playing guitar was his greatest passion and nothing kept him from it (besides a bad day of relentless pain.)

His love for music led him to co-found a music competition called 'Music for the Cause' with his daughter Elizabeth Seaton Schaurmann. The purpose was to give struggling artists a platform.... seeking the up-and-coming musicians looking to be found. It had a special focus within the hemophilia community. They successfully launched some amazing talent! And advanced awareness for this underserved genetic disorder across the country.

Julia Seaton Mascarro, his other daughter, has two sons who have shared the life of hemophilia with him. He's one of the oldest living persons with hemophilia in the country. He didn't sit idly. He successfully served on boards and actively pursued government changes to serve the hemophilia community and the medications that treat them. The industry is miles ahead of where it once was and he had much to do with it.

He was a true inspiration to all. He lived a great life and shared his joyful life with everyone he met.

When those we know are grieving, they need to hear that our hearts resonate with theirs. We too are suffering from the loss of Bob Seaton, whom we knew and respected -HFNC 

### IN THIS ISSUE



**WALK  
SPOTLIGHT**  
Page 5



**COVERED  
CALIFORNIA**  
Page 8



**THE FEMALE  
FACTOR  
RETREAT**  
Page 16



**KID'S  
PAGE**  
Page 17

# FACTOR UP with ALTUVIII<sup>TM</sup>

Higher-for-longer Factor VIII levels in the near-normal to normal range (**over 40%**) for most of the week

**ALTUVIII<sup>TM</sup>**  
Antihemophilic Factor (Recombinant),  
Fc-VWF-XTEN Fusion Protein-ehfI



## HIGHER FACTOR LEVELS FOR LONGER

Above 40% for most of the week (near-normal to normal range).<sup>\*†</sup>

## 48

## HOUR HALF-LIFE IN ADULTS

In a Phase 3 study,<sup>†</sup> ALTUVIII<sup>TM</sup> offered adults the longest half-life of any Factor VIII therapy.

## 0.7

## BLEEDS PER YEAR<sup>‡</sup>

Mean annual bleed rate observed in 128 people previously treated with prophylaxis therapy.<sup>†</sup>

In people taking ALTUVIII<sup>TM</sup> in the XTEND-1 study, 21% of people had headache, 16% had joint pain, and 6% had back pain

<sup>\*</sup>Average trough levels were 18% for adults 18 years and older, 9% for adolescents aged 12 years to under 18 years, 10% for children aged 6 years to under 12 years, and 7% for children aged 1 year to under 6 years.

<sup>†</sup>159 adults and adolescents with severe hemophilia (aged 12 years and older) were enrolled in the XTEND-1 study; 133 people were in Group 1 and switched to ALTUVIII<sup>TM</sup> prophylaxis from prior prophylaxis therapy. Efficacy of prophylaxis was evaluated in 128 of these patients.

<sup>‡</sup>Data based on treated bleeds.

## CONNECT WITH YOUR CoRe TODAY

Learn more about ALTUVIII<sup>TM</sup>, living with hemophilia, and treatment options from your local CoRe.



Cathy Marquez  
cathy.marquez@sanofi.com  
530-228-5403  
Serving NorCal

### INDICATION

ALTUVIII<sup>TM</sup> [antihemophilic factor (recombinant), Fc-VWF-XTEN fusion protein-ehfI] is an injectable medicine that is used to control and reduce the number of bleeding episodes in people with hemophilia A (congenital Factor VIII deficiency).

Your healthcare provider may give you ALTUVIII<sup>TM</sup> when you have surgery.

### IMPORTANT SAFETY INFORMATION

#### What is the most important information I need to know about ALTUVIII<sup>TM</sup>?

Do not attempt to give yourself an injection unless you have been taught how by your healthcare provider or hemophilia center. You must carefully follow your healthcare provider's instructions regarding the dose and schedule for injecting ALTUVIII<sup>TM</sup> so that your treatment will work best for you.

#### Who should not use ALTUVIII<sup>TM</sup>?

You should not use ALTUVIII<sup>TM</sup> if you have had an allergic reaction to it in the past.

#### What should I tell my healthcare provider before using ALTUVIII<sup>TM</sup>?

Tell your healthcare provider if you have had any medical problems, take any medications, including prescription and non-prescription medicines, supplements, or herbal medicines, are breastfeeding, or are pregnant or planning to become pregnant.

#### What are the possible side effects of ALTUVIII<sup>TM</sup>?

You can have an allergic reaction to ALTUVIII<sup>TM</sup>. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.

Your body can also make antibodies called "inhibitors" against ALTUVIII<sup>TM</sup>. This can stop ALTUVIII<sup>TM</sup> from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

The common side effects of ALTUVIII<sup>TM</sup> are headache, joint pain, and back pain.

These are not the only possible side effects of ALTUVIII<sup>TM</sup>. Tell your healthcare provider about any side effect that bothers you or does not go away.

Please see full [Prescribing Information](#).

**sanofi**

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MAT-US-2301368-v1.0-03/2023



## Dear HFNC Community,

As we approach the end of 2023 and the start of the new year, we cannot help but look back on everything we have experienced both individually and as a community this past year. This year has been truly amazing, with the release of a new gene therapy for those suffering with severe Hemophilia A, to compliment the gene therapy which was released for those with severe Hemophilia B in 2022, as well as other therapies which were FDA approved. Additionally, we can look forward to new therapies which will hopefully be approved for the treatment of various bleeding disorders in 2024 and 2025. For those in the bleeding disorders community worldwide, improved care and treatment is advancing at a rapid rate.

The work of this foundation and others like it throughout the nation is to improve the lives of those in the bleeding disorders regional community that we work within, to bring you valuable educational opportunities, to advocate with you and on your behalf with local, state and national elected officials, to help to improve your lives as we work to build and support a tighter and more inclusive bleeding disorders community.

We look to you, our community, for your ideas and suggestions as we move forward into 2024. As this time of year brings us together with our friends and family, let us also strive to embrace and support those within our bleeding disorders community here and around the world.

May your holiday season be filled with love and light.

Sincerely,



**Executive Director**

*Hemophilia Foundation of Northern California*

## Estimada comunidad de HFNC,

A medida que nos acercamos al final del 2023 y al inicio del Año Nuevo, no podemos evitar mirar hacia atrás y recordar todo, hemos experimentado tanto individualmente como en comunidad este año pasado. Este año ha sido verdaderamente sorprendente, con el lanzamiento de una nueva terapia genética para aquellos con el diagnóstico de hemofilia A severo, para complementar la terapia génica que se lanzó para aquellos con hemofilia B severo, en el 2022, así como otras terapias que fueron aprobadas por la FDA. Además, nosotros podemos esperar nuevas terapias que, con suerte, serán aprobadas para el tratamiento de diversos trastornos sanguíneos en el 2024 y 2025. Para aquellos en la comunidad de trastornos sanguíneos en todo el mundo, mejor atención y el tratamiento está avanzando a un ritmo rápido.

El trabajo de esta fundación y otras similares a través de la nación es mejorar las vidas de aquellos en la comunidad de trastornos sanguíneos con que trabajamos para brindarle valiosas oportunidades educativas, abogar con usted y en su nombre con las autoridades locales, funcionarios electos estatales y nacionales, para ayudar a mejorar sus vidas mientras trabajamos para construir y apoyar un sistema más unido y una comunidad de trastornos sanguíneos más inclusiva.

Esperamos de usted, nuestra comunidad, sus ideas y sugerencias a medida que avanzamos hacia el 2024. Como en este tiempo del año nos reunimos con nuestros amigos y familia, esforcémonos también por abrazar y apoyar a aquellos dentro de nuestra comunidad de trastornos sanguíneos aquí y alrededor del mundo.

Que tus fiestas estén llenas de amor y luz.

Sinceramente,



**Directora Ejecutiva**

*Hemophilia Foundation of Northern California*

It feels like the world has stopped in honor of a great man. We were so sorry to hear of the passing of our community member and friend, Bob Seaton. Bob volunteered in many capacities at HFNC. He served as a board member, facilitated Blood Brotherhood meetings, was a huge donor at our annual golf event and partnered with us with his non-profit, Music for The Cause, hosting the Fishing Derby. We will always hold him in such high regard for providing a benefit to everyone he served. - HFNC

Se siente como si el mundo se hubiera detenido en honor a un gran hombre. Lamentamos mucho el fallecimiento de nuestro amigo y miembro de la comunidad, Bob Seaton. Bob se ofreció como voluntario en muchas capacidades en HFNC. Se desempeñó como miembro de la junta directiva, facilitó reuniones de Blood Brotherhood, fue un gran donante en nuestro evento de golf anual y se asoció con nosotros con su organización sin fines de lucro, Music for The Cause, para organizar el Fishing Derby. Siempre lo tendremos en tan alta estima por brindar un beneficio a todas las personas a las que sirvió. - HFNC

**Dear friends,**

This has been a surprising first year for me as president of the board of directors. I have been surprised by the high quality of the presentations we have provided and surprised by the low turnout at these events. There may be some trepidation about gathering together in the current COVID environment. Perhaps our bleeding disorders are so well managed that we no longer need the kind of educational programming we provide?

My family was always involved in the local chapter as I was growing up. We found these relationships with other families to be invaluable, both for tips and emotional support. As I grew older, we became that family that others turned to in times of need.

I would like to see our foundation once again become that place where folks meet and support one another, particularly those that are newly diagnosed and overwhelmed. I hope to see you at our next event.

Thank you,



**Randall G. Curtis,**  
*MBA President of the Board*

**Queridos amigos,**

Este ha sido un primer año sorprendente para mí como presidente de la Junta Directiva. Me ha sorprendido por la alta calidad de las presentaciones que hemos ofrecido y sorprendido por la baja asistencia a estos eventos. Es posible que haya cierta inquietud por reunirse en el clima actual de COVID. Tal vez nuestros trastornos hemorrágicos estén tan bien controlados que ya no necesitemos el tipo de programa educativo que ofrecemos. ¿Necesitamos el tipo de programa educativo que ofrecemos?

Durante mi infancia, mi familia siempre participó en la sección local. Para nosotros, las relaciones con otras familias eran muy valiosas, tanto por los consejos que nos daban y el apoyo emocional que nos brindaban. A medida que fui creciendo, nos convertimos en esa familia a la que otros se acercaban en momentos de necesidad.

Me gustaría que nuestra fundación volviera a ser ese lugar donde la gente se reúne y se apoya mutuamente, en particular los que están recién diagnosticados y abrumados. Espero verlos en nuestro próximo evento.

Muchas gracias,



**Randall G. Curtis,**  
*MBA President of the Board*



GOAL \$100,000

**\$162,031**  
RAISED

Join the Cause  
A big thank you to all  
who contributed  
to the UNITE for Bleeding  
Disorders Walk.  
From donors and  
fundraisers to  
volunteers, sponsors, and  
walkers, your support  
is invaluable!



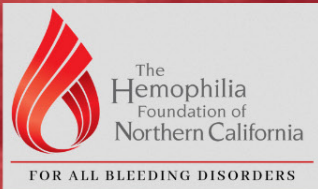
Kindly scan the  
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Act Now! Don't Miss Your  
Opportunity to Make a  
Difference!

Your donation can still have  
a significant impact.

[CLICK HERE TO DONATE TODAY.](#)







We have had so much love and support over the years and this annual walk gives us the opportunity to see all of our family and friends, ones that have walked with us each year since 2017 and new friends that have come into our lives more recently. We know that as the kids get older and jump into sports there will be less stroller pushing and more scooter riding, we also know it gets more and more difficult to plan around life.

We hope that by walking we will continue to see improvements in drug options and we can send kids with bleeding disorders to Camp Hemotion."

### Colin's Crew

*UNITE for Bleeding Disorders Team*

**Goal \$5000, Raised \$30,265**

### Thank you to

Colin's Crew, Craiger's Raiders, Kurtie's Birdies, Keiji's All Stars, A Touch of Scarlett, Camp Hemotion, Huddy Buddy, BioMarin, Max Factor, Bayer Teams, Lan Clan, Genentech, Marc Pangilinan, Optum Stronger Together, Team Sanofi, Young Hemos, The Harlan Family Band, HF Healthcare Heroes, Team TomTom, UCSF Benioff Children's Hospital, NOR-CAL COAG'er!!

***You are incredible!!***



Hemos tenido tanto amor y apoyo a lo largo de los años y esta caminata anual nos da la oportunidad de ver a toda nuestra familia y amigos, los que han caminado con nosotros cada año desde 2017 y los nuevos amigos que han llegado a nuestras vidas más recientemente. Sabemos que a medida que los niños crecen y saltan a los deportes habrá menos empuje de cochecito y más paseo en scooter, también sabemos que cada vez es más difícil planear alrededor de la vida.

Esperamos que al caminar sigamos viendo mejores opciones de medicamentos y podamos mandar niños con trastornos hemorrágicos al Campamento Hemotion"

### Colin's Crew

*UNITE for Bleeding Disorders Team*

**Meta \$5000, Recaudado \$30,265**

### Gracias a

Colin's Crew, Craiger's Raiders, Kurtie's Birdies, Keiji's All Stars, A Touch of Scarlett, Camp Hemotion, Huddy Buddy, BioMarin, Max Factor, Bayer Teams, Lan Clan, Genentech, Marc Pangilinan, Optum Stronger Together, Team Sanofi, Young Hemos, The Harlan Family Band, HF Healthcare Heroes, Team TomTom, UCSF Benioff Children's Hospital, NOR-CAL COAG'er!!

***¡¡Eres increíble!!***

# Lucky Me

*Pamela Lauer*



**15 hours after getting help infusing at my local ED I am still picking flakes of my blood out of my cuticles.** I had to cancel my long awaited acupuncture appointment today and the work I was going to get done on my car. I still can't drive or hardly walk right. My ankle bleed yesterday was just from a short two mile walk, a walk I do all the time. Worse, I am on a drug meant to stop this. Break through bleeds are supposed to be rare.

Instead my HTC says I am rare. A female mild hemophilia A that for some reason bleeds like a severe sometimes and other times I am fine for months. Taking this drug has helped curb the constant trickle I experience in my target knee but overall, I am worried that it is not working well enough. Its so hard when I can't see what is going on in there, so weird that bleeders hardly ever seen their blood...unless in a syringe flush.

At the ER last night the nurse knew me by name. He always says, "I am I sorry to see you!" when I come in. A not so funny joke.

He knows my veins are a pain but sees I have been working on strengthening my hands and tries a vein in my right hand way up by my knuckle. The poke is extra painful in this super sensitive spot. He is trying to avoid the scarred up spot I always try in that hand. The flush of blood is there but the saline won't push in, the vein swells and blows up. He has to pull the needle and my blood pours out of my hand and all over the floor like a waterfall before he can grab the gauze to sop it up.

"See, told you I am bleeding." No one laughs.

He reverts to my "elbow pit" and gets it first try. He adds a "pony" so I can self administer then goes to the check in counter to complain that they entered my visit incorrectly on the paperwork.

"She is in here all the time, Mike! Can't you remember how we billed this last time?"

His words hit me hard as I press on my factor recombinant and watch the clock.

I am not sure why this is happening to me. I have only been taking factor for a few years. It seems like my bleeds are increasing with age. I am pre-menopause but it may be closer than I think since they took my uterus in 2014.

My aunt (who has 4 kids with hemophilia) says she never got diagnosed but does remember terrible bruises. As she aged the bleeds seemed to subside. I don't know how, but somehow, I am experiencing the opposite problem. My bleeds seem to increase as I age. Luckily, though, my son is not affected. I will never stop thanking my lucky stars for that. I am thinking about that as I wipe a tear from my cheek as I drive home from the ER, my teenager in the passenger seat.

"Sorry you had to wait for me, I hope you still have time to get all your homework done."

"Yeah, I'll pull it off. Sorry you got hurt again."

"I am just so glad your aren't dealing with this. I am so glad you were born okay. I would take all this pain ten times over to ensure you never have to deal with it." 🔥

**Jivi**  
antihemophilic factor  
(recombinant) PEGylated-auid

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# IMPORTANT

# IMPORTANTE

## ANNOUNCEMENT



### Individual Mandate Funds Dramatic Cost-Sharing Reductions for Covered California

Covered California announced in July that it will use \$82.5 million appropriated by the legislature in the 2024 budget to dramatically reduce out-of-pocket costs for lower-income enrollees.

The state-based ACA Marketplace will make the subsidies available to those earning less than 250 percent of the federal poverty level (or about \$34,000 per year). This represents just over one-third of Covered California's 1.75 million enrollees. The move will eliminate deductibles entirely for all three silver-tier cost-sharing reduction plans. Other benefits will vary by plan but include lower generic drug costs and copays for primary care, emergency care and specialist visits, as well as lower annual out-of-pocket maximum limits.

The latest cost-sharing reductions will help to shield most Covered California enrollees from the 9.6 percent average increase in premiums for 2024, which officials attribute to higher utilization after the pandemic, as well as the rising cost of health services and labor shortages. (Rates had increased by less than two percent on average during the pandemic but 5.6 percent for 2023).

## ANUNCIO



### El mandato individual financia drásticas reducciones de los gastos compartidos para Covered California

Covered California anunció en julio que utilizará 82.5 millones de dólares asignados por la legislatura en el presupuesto de 2024 para reducir drásticamente los gastos de bolsillo de los afiliados con ingresos más bajos.

El mercado estatal de la ACA pondrá los subsidios a disposición de quienes ganen menos del 250% del nivel federal de pobreza (unos 34,000 dólares al año). Esto representa algo más de un tercio de los 1.75 millones de afiliados a Covered California. La medida eliminará por completo las franquicias en los tres planes de reducción de costes compartidos de la categoría plata. Otros beneficios variarán según el plan, pero incluyen menores costes de medicamentos genéricos y copagos por atención primaria, atención de emergencia y visitas a especialistas, así como menores límites máximos anuales de desembolso.

Las últimas reducciones de los gastos compartidos ayudarán a proteger a la mayoría de los afiliados a Covered California del aumento medio del 9.6% de las primas para 2024, que los funcionarios atribuyen a una mayor utilización tras la pandemia, así como al aumento del coste de los servicios de salud y a la falta de mano de obra. (Las tarifas habían aumentado menos de un dos por ciento de media durante la pandemia, pero un 5.6 por ciento para 2023).



TO YOU AND YOUR FAMILY

# Happy Holidays

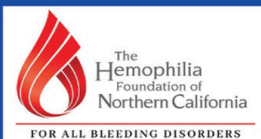
WE WISH YOU AND THOSE YOU LOVE A VERY JOYOUS SEASON AND HAPPY NEW YEAR

Yours, HFNC Staff and Board



## HFNC Men's Meetup

For men and those that identify as male with a bleeding disorder



January 27, 2024  
3PM-6PM PT



K-Taping with Dr. Mike Zolotnitsky



### Tee-up a great day with your bleeding disorders brothers

- HFNC's first Men's Meetup
- Pre-golf stretching, talk about mobility and K-Taping
- Mosi Williams, MSW, facilitator
- Ivan Giron, co-facilitator

**YOU MUST HAVE A BLEEDING DISORDER TO ATTEND**

**Ages 18+**  
**No childcare provided**  
 please make other arrangements for children

Entry is FREE | Dinner provided

**Topgolf**  
 10 Topgolf Drive  
 San Jose, CA

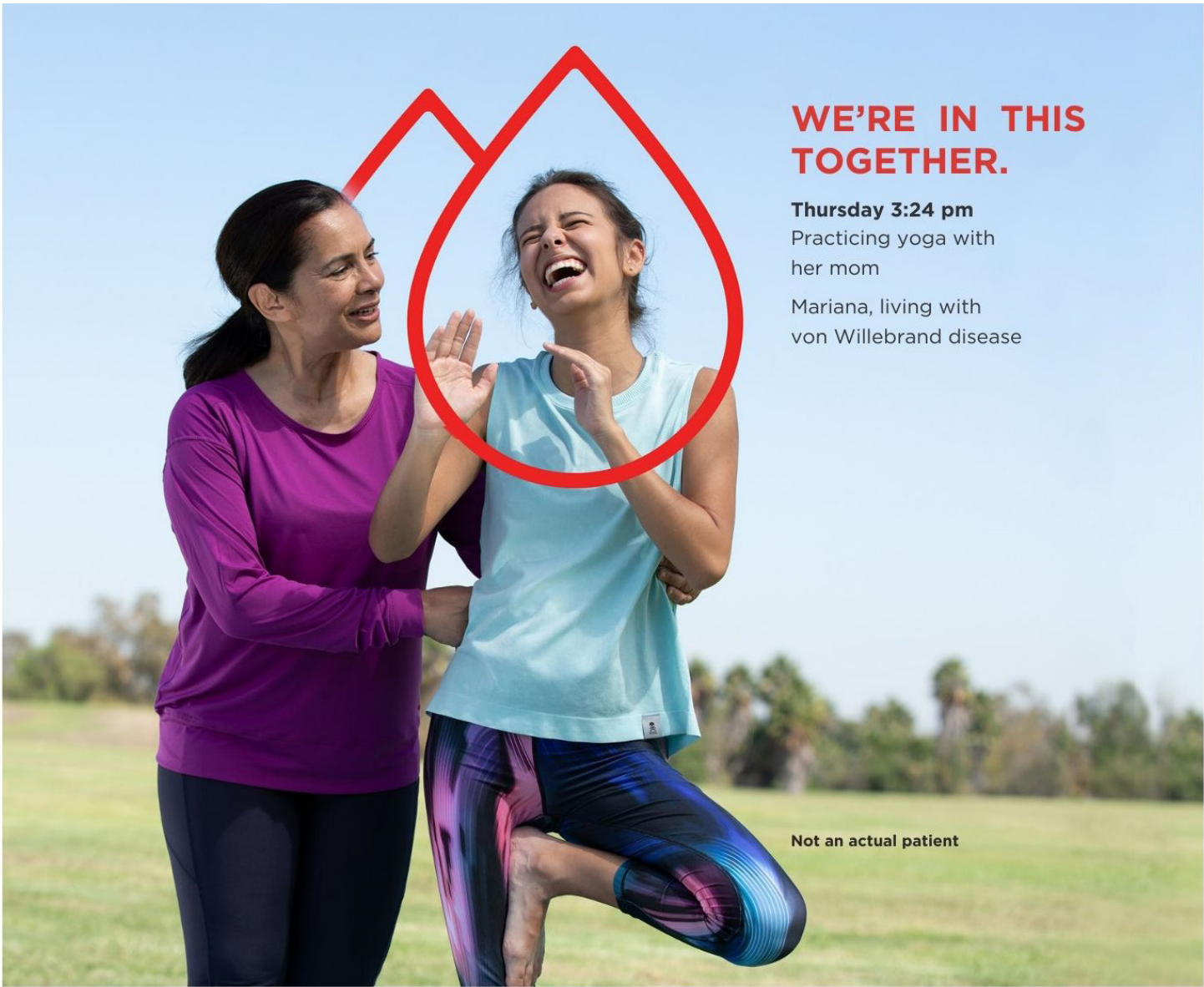


You must be registered to attend  
[hemofoundation.org/events](https://hemofoundation.org/events)  
 or call/text  
 510.658.3324



Scan Here





**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.*

 | 

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Familia de Sangre is a gathering of over 700 Spanish-speaking individuals with blood disorders in the United States. It offers language-inclusive education, resources and a supportive community for those navigating diagnosis, care, and treatment. The event fosters friendships and connections among attendees and welcomes caregivers, parents, and siblings. The next gathering will be held in Anaheim, California, in 2024.

The Familia de Sangre gathering has become an important annual event for many members of the Spanish-speaking community with blood disorders, providing a unique opportunity to share experiences, ask questions, and learn from one another. The program includes informational sessions on topics such as managing symptoms, navigating insurance, and finding emotional support. Attendees can also participate in fun activities like art workshops and dance classes, which allow them to connect with others in a relaxed and enjoyable setting.

One of the key benefits of Familia de Sangre is the sense of community it provides. Many people with blood disorders feel isolated and alone, especially if they live in areas where there are few resources or support groups. By bringing together hundreds of individuals from across the country, Familia de Sangre creates a space where people can feel understood and supported.

Caregivers, parents, and siblings are also welcome at the gathering. For many families, a blood disorder diagnosis can be overwhelming and frightening. Familia de Sangre offers resources and support for those who are navigating the challenges of caring for a loved one with a blood disorder. By bringing together individuals and families affected by these conditions, Familia de Sangre is helping to build a stronger, more resilient community.



Familia de Sangre es una reunión de más de 700 hispanohablantes con trastornos hemorrágicos en los Estados Unidos. Ofrece información en español, recursos y una comunidad de apoyo para quienes se enfrentan al diagnóstico, los tratamientos y los servicios de salud. El evento fomenta amistades y conexiones entre los asistentes y da la bienvenida a cuidadores, padres y hermanos. El próximo encuentro se celebrará en Anaheim, California, en 2024.

El evento de Familia de Sangre se ha convertido en una cita anual importante para muchos miembros de la comunidad hispanohablante con trastornos hemorrágicos, ya que ofrece una oportunidad única para compartir experiencias, hacer preguntas y aprender unos de otros. El programa incluye sesiones informativas sobre temas como el control de los síntomas, la navegación por los seguros y la búsqueda de apoyo emocional. Los asistentes también pueden participar en actividades divertidas como talleres de arte y clases de baile, que les permiten conectar con otras personas en un ambiente relajado y agradable.

Uno de los principales beneficios de Familia de Sangre es el sentido de comunidad que proporciona. Muchas personas con trastornos hemorrágicos se sienten aisladas y solas, especialmente si viven en zonas donde hay pocos recursos o grupos de apoyo. Al reunir a cientos de personas de todo el país, Familia de Sangre crea un espacio en el que la gente puede sentirse comprendida y apoyada.

Los cuidadores, padres y hermanos también son bienvenidos a la reunión. Para muchas familias, el diagnóstico de un trastorno sanguíneo puede ser difícil y frustrante. Familia de Sangre ofrece recursos y apoyo a quienes se enfrentan a los retos de cuidar a un ser querido con un trastorno sanguíneo. Al reunir a personas y familias afectadas por estas enfermedades, Familia de Sangre ayuda a construir una comunidad más fuerte y resistente.





FAMILIA DE SANGRE



FAMILIA DE SANGRE







FAMILIA DE SANGRE



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FOR ALL BLEEDING DISORDERS

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www.hemofoundation.org

Creating  
a Lifeline of  
Community  
and Support

Dear HFNC Community Member:

Truly, for the first time since before the COVID pandemic began, the community was able to gather and enjoy learning and laughing together at almost all of our regularly scheduled foundation events. This allowed the foundation to be able to host Camp Hemotion 2023 and with the help of our stellar group of camp volunteers, it was a huge success as campers and counselors alike, gathered together in Oakhurst, CA to hug friends whom had not been seen in person in years, to meet new friends, to share a common bond, make memories and build that sense of community that flourishes at summer camp.

The importance of Camp Hemotion and other programs and events which HFNC hosts for our community each year cannot be understated. We exist to provide a service to you, our community member, but we cannot provide that service without your help. We are asking you to consider a contribution to the Hemophilia Foundation of Northern California to support our important work. You may contribute in a variety of ways and if your family has limited financial resources, you might consider the following suggestions:

- Ask people you know if they would consider making a gift to the organization during this season of holiday giving. Let people know that any gift of any size is both appreciated and goes directly to help families and children.
- Donate to our UNITE for Bleeding Disorders walk! Ask at least two additional people to match your donation. YOUR donations provide critical services.
- Check with your employer (or with family and friends) to see if their company has a matching gift program. 90% of employees do not use their matching gift amounts.
- Make a special contribution to honor a loved one.

Please consider HFNC in your giving plans this year so that we may continue our work to support families and kids affected by bleeding disorders. Please scan the code below or go to our website to make your personal contribution.

With warm regards,

Randall Curtis  
HFNC Board President

Andrea Orozco  
HFNC Executive Director

\*\*\*HFNC is a 501(c)3 organization and our Federal Tax ID No. is 94-1638703

### Executive Committee

**Randall G. Curtis**  
President

**Dawn Pollard**  
Vice President

**Derek Sim**  
Secretary

**Anita Bawa**  
Treasurer

### Board Members

**Michael Bradley**

**Mark Helm**

**Elaine Lai**

**Marc Pangilinan**

**Mosi Williams**

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**Andrea Orozco**  
Executive Director

**Ashley Gregory**  
Education and Advocacy  
Director

**Pedro Preciado**  
Community Outreach  
Coordinator





FOR ALL BLEEDING DISORDERS

1155-C Arnold Drive, #236, Martinez, CA 94553  
P: 510.658.3324 F: 510.658.3384  
www.hemofoundation.org

## Creating a Lifeline of Community and Support

Estimado miembro de la comunidad HFNC:

Verdaderamente, por primera vez desde antes de que comenzara la pandemia de COVID, la comunidad pudo reunirse para disfrutar, aprender y reír juntos en casi todos los eventos de nuestra fundación. Esto permitió a la fundación poder organizar el Campamento Hemotion 2023 y con la ayuda de nuestro grupo estelar de voluntarios del campamento, fue un gran éxito para los campistas y consejeros por igual, se reunieron en Oakhurst, CA para abrazar a los amigos que no habían visto en persona en años, para conocer nuevos amigos, para compartir un vínculo común, hacer recuerdos y construir ese sentido de comunidad que florece en el campamento de verano.

La importancia de Camp Hemotion y otros programas y eventos que HFNC organiza para nuestra comunidad cada año no puede ser subestimada. Existimos para ofrecer un servicio a usted, nuestro miembros de la comunidad, pero no podemos ofrecer ese servicio sin su ayuda. Le pedimos que considere una contribución a la Fundación de Hemofilia del Norte de California para apoyar nuestro importante trabajo. Usted puede contribuir en una variedad de maneras y si su familia tiene recursos financieros limitados, puede considerar las siguientes sugerencias:

- Pregunte a sus conocidos si considerarían la posibilidad de hacer un regalo a la organización durante estas festividades. Hágales saber que cualquier regalo, independientemente de su cuantía, es apreciado y se destina directamente a ayudar a familias y niños.
- Haz un donativo para la marcha UNITE for Bleeding Disorders walk! Pida al menos a otras dos personas que igualen su donación. SUS donaciones proporcionan servicios críticos.
- Consulte a su empleador (o a familiares y amigos) si su empresa tiene un programa de donaciones de contrapartida. El 90% de los empleados no utilizan las cantidades de sus donaciones de contrapartida.
- Haga una contribución especial para honrar a un ser querido.

Por favor, tenga en cuenta a HFNC en sus planes de donaciones de este año para que podamos continuar nuestro trabajo de apoyo a las familias y niños afectados por trastornos hemorrágicos. Escanee el código siguiente o visite a nuestro sitio web para hacer su contribución personal.

Saludos cordiales,

Randall Curtis  
HFNC Board President

Andrea Orozco  
HFNC Executive Director

\*\*\*HFNC es una organización 501(c)3 y nuestro número de identificación fiscal federal es 94-1638703.

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Community Outreach  
Coordinator



Including  
Daily breakfast, snacks, lunch, dinner  
Education provided by HTC  
Middle Eastern Dancing  
Activities/Vendor visits/Prizes  
Recreation time/Campfire/Beach



# THE FEMALE FACTOR RETREAT FEBRUARY 16-18, 2024

## Single Room

\$215

Escape to the ultimate beach retreat in your own room with private bath



Scan to Register

## Double Room

\$175 & \$80 for child

Enjoy with a roommate!  
Mothers & daughters, sisters, friends ages 12 & up (minors must be accompanied by their guardian) are welcome to an exclusive shared room with private bath. Limited selection available

## What to Expect

Friday - Sunday enjoy women, girls and those that identify in the bleeding disorders community as female as we become educated, empowered and enriched for the weekend where all your meals, lodging and activities are included at the oceanside!

[hemofoundation.org](http://hemofoundation.org)    510.658.3324    [ashley.gregory@hemofoundation.org](mailto:ashley.gregory@hemofoundation.org)





# Kid's Page

...and playful adults!



## JOKES FOR WINTER GIGGLES:

*Q: What are Frosty's parents' names?  
What about his brother?*

*A: Mom and Pop Sicle and little brother Ice Sicle!!!*

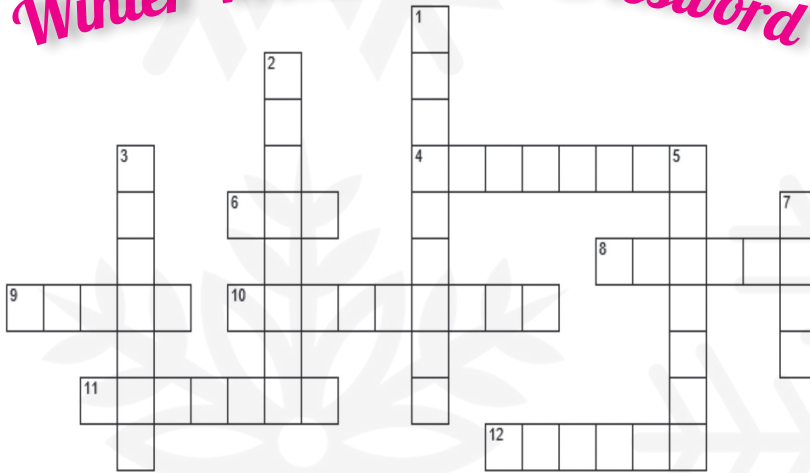
*Q: What did one Snowman say to  
the other?*

*A: "Hey, do you smell carrots too?"*



©OFFICIALSHOEBOX

## Winter Wonderland Crossword



### ACROSS

- 4 What you wear on your ears to keep them warm
- 6 What you get when water freezes
- 8 What you use to remove snow from the sidewalk
- 9 What you wear on your feet to keep them warm
- 10 (2-words) what you put on your feet to glide across the ice.
- 11 You build him by stacking large snowballs on top of each other then adding a scarf and a hat.
- 12 A sport played on an ice rink

### DOWN

- 1 What you might sit in front of to warm up.
- 2 (2-words) what you drink to warm up after playing outside
- 3 What you wear on your hands to keep them warm.
- 5 What it is called when school is cancelled due to snow.
- 7 What you sit in when going down the hill.



*What could you add to  
the Snowman above?*

## CALENDAR

### DECEMBER

12/1/23	World AIDS Day	AIDS Memorial Golden Gate Park San Francisco, CA
12/10/23	WinterFest	Fresno
12/12/23	Board Meeting	Virtual
12/24/23	Christmas Eve	Holiday HFNC closed
12/26/23	Christmas Day	Holiday HFNC closed
12/24/23-12/31/23	HFNC Office Closed	Holiday HFNC closed

### JANUARY

1/1/24	New Year's Day	Holiday HFNC closed
1/9/24	Board Meeting	Virtual
1/15/24	MLK Jr Day	Holiday HFNC closed

### FEBRUARY

2/9/24-2/12/24	YETI Conference	Camp Collins, OR
2/13/24	Board Meeting	Virtual
2/16/24-2/18/24	The Female Factor Retreat	Villa Maria del Mar Santa Cruz
2/19/24	President's Day	Holiday HFNC closed
2/29/24	Rare Disease Day	TBD
2/29/24	CA Rare Disease Access Coalition (formerly Health Policy Summit)	Sacramento and Virtual

### MARCH

3/1/24-3/31/24	Bleeding Disorders Awareness Month	YOUR City
3/6/24-3/8/24	NBDF Washington Days	Washington DC
3/8/24-3/10/24	Family Camp	The Taylor Family Foundation, Camp Arroyo, Livermore, CA
3/12/24	Board Meeting	Virtual
3/16/24-3/19/24	Future Leaders Program HCC	Sacramento CA
3/18/24	Legislation Day	Sacramento CA
3/31/24	Easter	Holiday HFNC closed

### APRIL

4/9/24	Board Meeting	Virtual
4/11/24-4/14/24	Hemophilia Federation of America Annual Symposium	Indianapolis, IN
4/17/24	World Hemophilia Day/ Annual Meeting/Feed	Concord
4/26/24-4/28/24	Western States Region IX Conference	Valley Children's Hospital, Fresno, 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.hemophilia.org/>

*NBDF Chapters (See full list at NBDF)*

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

### HEMOPHILIA TREATMENT CENTERS HTC's

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

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

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

University of California San Francisco

[https://www.ucsfhealth.org/clinics/hemophiliatreatment\\_center/](https://www.ucsfhealth.org/clinics/hemophiliatreatment_center/)

Valley Children's Hospital

<https://www.valleychildrens.org/>



# WHAT'S NEXT? YOU DECIDE.



At Genentech, we're committed to creating programs for you, with you. From a web series focused on finding the *magic* in life, to a tournament for gamers, to workshops designed to help you think well, do well, and be well, we're here to help you take on what comes next.

VISIT [GENENTECHHEMOPHILIA.COM](https://www.genentechhemophilia.com)  
TO SEE HOW WE'RE CREATING  
WHAT'S NEXT, TOGETHER.

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

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