

# HEMOPHILIA ACTION



Hemophilia Foundation  
of Southern California

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## IN THIS ISSUE:

2023  
FAMILIA DE  
SANGRE

9TH ANNUAL  
BACK TO  
SCHOOL

CAMP BLOOD  
BROTHERS  
AND SISTERS

SHAKA SURF FEST 2023  
Full article on page 11!

HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA

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# THANK YOU DONORS

**HEMOPHILIA**ACTION is published quarterly by  
THE HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA

## GENERAL

Anonymous (2) • Erik and Carolina Bowers • Daisy Cortes • William Hartman • Steve Lowe  
Diana Parker • Perry Parker • Jeffrey and Mary Lou Wright

## IN HONOR

Michael Bennett, in honor of Perry Parker  
Harry and Juanita Boessler, in honor of Tyler, Abby and Michael  
Jane Brady, in honor of Amelie Iavicoli  
Timothy R. Thomas and Sarah E. Clark Foundation, in honor of Dr. Doris Quon

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## 2023 CALENDAR

### CENA DE MUJERES ENLAZADAS

November 2 • Luminarias, Monterey Park, CA

### 15TH ANNUAL SOCAL UNITE WALK AND HEALTH FAIR

November 4 • The Meadows at Whittier Narrows,  
South El Monte, CA

### SNOWFLAKE DINNER

November 28 • Riverside, CA

### SNOWFLAKE DINNER

November 30 • Monterey Park, CA

### SNOWFLAKE DINNER

December 3 • Bakersfield, CA

### SNOWFLAKE DINNER

December 4 • Santa Barbara, CA

### SNOWFLAKE DINNER

December 5 • Burbank, CA

### SNOWFLAKE DINNER

December 6 • Rancho Cucamonga, CA

### SNOWFLAKE DINNER

December 7 • Lancaster, CA

### SNOWFLAKE DINNER

December 13 • Orange County, CA

*\*Snowflake Dinner dates subject to change*

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## A LETTER FROM THE BOARD PRESIDENT

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In September, my family and I had the pleasure of attending Familia de Sangre, the largest Spanish-speaking bleeding disorders conference in the country, hosted by all 4 California chapters. This conference provided support and education for more than 650 community members and covered topics such as mental health, nutrition, financial education, and advocacy. It was wonderful seeing so many of you there and watching the connections families were making with one another.

I am now looking forward to our superhero-themed 15th Annual Unite for Bleeding Disorders Walk & Health Fair, which will take place at Whittier Narrows on November 4. In order to raise even more funds in support of our community, we are hosting an online auction this year to take place around the time of the Walk –

please reach out to Michele Warner with any questions, at [mwarner@hemosocal.org](mailto:mwarner@hemosocal.org).

The walk is our largest fundraising event of the year, with funds raised supporting Camp Blood Brothers & Sisters, educational programs, emergency financial assistance, scholarships, and research. It's not too late to win a Factor Club medal for raising \$500 or more, or to receive your fundraising giveaways! You have until December 31 to make your gift; just visit [www.uniteforbleedingdisorders.org/event/socal](http://www.uniteforbleedingdisorders.org/event/socal)!

I look forward to seeing you all again very soon! In the meantime, please feel free to reach out to me with any questions or if I can help in any way.

- Rick Kelley, MBA

## A LETTER FROM THE EXECUTIVE DIRECTOR

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The Fall season has proven to be an exhilarating whirlwind of events for our community. From the end of summer camp to the bustling back-to-school preparations, we seamlessly transitioned into a calendar packed with exciting activities. The highlight of the season was undoubtedly the Familia de Sangre Conference, where we gathered as a tight-knit family to celebrate our shared heritage and values. The conference not only deepened our connections, but inspired us to continue working together toward our common goals. Amidst the hectic Fall schedule, we managed to squeeze in some moments of relaxation and adventure. A collective trip to the beach for a day of surfing provided the perfect opportunity to bond and unwind. It was a testament to our unity and support for one another that we were able to navigate this busy season with such grace and enthusiasm.

This year, I experienced several firsts. I attended Camp Blood Brothers and Sisters at the Painted Turtle. The experience was truly unforgettable. I was able to see firsthand how the Painted Turtle created an experience for our campers that was full of fun, laughter, and paint. During our Shaka Surf and Beach Day, I rode the waves for the very first time. It was an experience full of anxiety, nervousness, and a bit of fear. Thank you to Dr. Shawn Whelan who reminded us that we must have courage to try new experiences and be ready to surf the waves of life. And like most things in life, after my first wipeout, I laughed, looked around to see who had seen me, and just turned back, jumped on my surfboard and paddled out to ride the next wave.

Together, we've proven that no challenge is too great, and no schedule too packed when we come together as a community. As we head into the rest of the year, we do so with hearts full of gratitude and excitement for all that the future holds for our remarkable group.

- Rigo Garcia, MPH



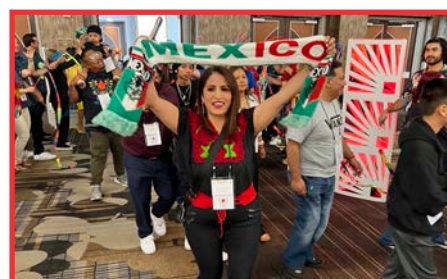
# 2023 FAMILIA DE SANGRE

Del 8 al 10 de septiembre, Familia de Sangre (FDS), la conferencia de trastornos sanguíneos más grande de habla hispana, marcó un hito histórico al celebrar su séptimo año con un logro sin precedentes: la celebración de nuestra conferencia más grande hasta la fecha, que recibió con entusiasmo a casi 700 increíbles miembros de la comunidad de todo el país y del extranjero.

Este notable acontecimiento fue posible gracias a los esfuerzos de colaboración de las organizaciones de hemofilia de California, incluidas la Hemophilia Foundation Southern California, la Hemophilia Foundation of Northern California, la Central California Hemophilia Foundation y la Hemophilia Association of San Diego County. Juntos, el evento fue un testimonio de la fuerza duradera y la unidad que definen a nuestra comunidad única.

A lo largo del evento, los asistentes disfrutaron de un tesoro de experiencias. Las sesiones educativas trataron una serie de temas cruciales, desde la salud mental hasta la nutrición, la actividad física y la educación financiera. Una demostración de cocina en directo mostró cómo adoptar un estilo de vida saludable al tiempo que se controlan los trastornos sanguíneos, mientras que los debates sobre promoción encendieron la pasión y el compromiso de los miembros de nuestra comunidad. Como gran colofón, los asistentes disfrutaron de la noche de clausura en el encantador Disneyland, estrechando los lazos de amistad y camaradería que caracterizan a Familia de Sangre.

Extendemos nuestra más sincera gratitud a todos nuestros patrocinadores, dedicados voluntarios y miembros de la comunidad que se unieron con nosotros en esta celebración de unidad y conocimiento. ¡Nos vemos en el FDS 2024!



## THANK YOU TO OUR SPONSORS!

### DIAMOND



### PLATINUM



### GOLD



### SILVER



### BRONZE





# 9TH ANNUAL BACK TO SCHOOL SYMPOSIUM

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On August 5, HFSC hosted the 9th Annual Back to School Educational Symposium at Cal Poly Pomona. Attendees received education on student rights in school and information on IEP, IHP, and 504 Plans.

Adults attended "The Basics of School Advocacy," presented in both English and Spanish by Gayle Hinazumi, SELPA Director, Retired, Monica Argumaniz, SLPA/SLP, and Celeste Cardenas-Gasio, M. Ed. Parents learned in addition to a specialized plan, students should also have an Emergency Care Plan in the event of a bleeding disorders emergency at school, which gives actions for faculty and staff to follow until medical help arrives.

The teens took a campus tour with students from Cal Poly Pomona, exploring what a college campus looks like, and hearing about programs from the tour guides. Following the tour, teens had a Q&A session with the Cal Poly students, as well as HFSC members who recently attended college. Thank you to community members Carson Knight and Zenaida Sanchez for sharing your experiences, and to Shazia Torres and Luisa Winter from Cal Poly Pomona's Office of Student Success for coordinating the campus tour and sharing their college experiences with the teens.

At the end of the event, students chose a new backpack and were provided with a school supply gift card for the school year. Thank you to all our wonderful volunteers for assisting us at this event and thank you to our wonderful sponsors!



## 2023 BLEEDING DISORDERS CONFERENCE

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HFSC attended The 75th Annual Bleeding Disorders Conference (BDC) that took place from August 17 to 19, 2023 at the Gaylord National Resort & Convention Center in National Harbor, Maryland. During the conference, HFSC participated in various breakout sessions, which included sessions on diversity, equity and inclusion, working with various partners, and tools to continue to improve resources for our community.

This 75th anniversary edition of the Bleeding Disorders Conference was also a momentous celebration for the rebranding of the organization. NHF is now known as the National Bleeding Disorders Foundation (NBDF). Their focus of work will not change but the new name change is expected to include all who are part of the bleeding disorders community.

NBDF also honored two of our amazing local heroes. Congratulations to Dr. Doris Quon, from Orthopaedic Hospital in Los Angeles, who won the Physician of the Year Award and Jennifer Donkin, from Children's Hospital Los Angeles, who won Nurse of the Year Award. Congratulation to our amazing winners, who we truly appreciate.



## 2023 SCHOLARSHIPS

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This summer, the HFSC scholarship committee granted 14 scholars with awards of \$500-\$1,000 toward furthering their education with one of three scholarships we offer each year. Thank you to our scholarship donors as well as to all who fundraise during Bleeding Disorders Awareness Month and at the Unite Walk to support our community members in their educational goals!

### 2023 CHRISTOPHER MARK PITKIN MEMORIAL SCHOLARSHIP

This scholarship fund has been created to honor the memory of Chris Pitkin, health policy consultant and advocate, a leader in the hemophilia community, former president of the Foundation, and a beloved friend of many.

#### ***Christian Elias***

Growing up I have always been an energetic, talkative, and outgoing individual that just wants to be active and never letting anything or anyone put me down. Everyday I have a huge confidence in myself that I will make the right decisions and be a better person. Not a day goes by where I do not feel like myself. I always come to the realization that the only person that I should be better than, is myself.

#### ***Joseph Cook***

My name is Joseph Cook and I will soon be a senior at Northern Arizona University in Flagstaff. I am majoring in criminal justice with a minor in psychology and a certificate in emergency management. I enjoy camping, hiking and being outdoors.

#### ***Emily DeLaFuente***

My name is Emily De La Fuente and I am a graduating senior in high school going to the University of California, Merced. I have always been involved within the Hemophilia community since I was a child since my two older brothers have Hemophilia A Severe, including my mother and I, who are carriers of Hemophilia. I have devoted much of my time to this community and I am always delighted to meet new people and hear the latest stories of this growing and welcoming community.

#### ***Charlie Franzen***

Hello, I'm Charlie Franzen, I will be attending the University of San Diego. I was diagnosed with hemophilia B at a young age, I have used my resilience and determination not only to manage my hemophilia but also to excel in my athletic and academic passions. I have the ambition of deepening my knowledge and contributing to the hemophilia Community, and inspiring others who face similar challenges.

#### ***Jarett Guillow***

Jarett Guillow is a medical student attending the University of California, Riverside School of Medicine. He has completed his 2nd year and is now beginning to work at various Southern Californian Hospitals affiliated with UCR. He has had a passion and drive to be a doctor since he was young and continues to pursue his career aspirations of becoming a Pediatric Hematologist/Oncologist.

#### ***Marcus Thomas***

I am a UX Design major at Arizona State University, and my dream is to blend my passion for XR with my love of game design so that I can one day start my own game studio. I want to make games in which people can be inspired by the future of tech entertainment...in different realities. I am an Afro-Latino Los Angeles native (a Valley Boy to be precise) that comes from a family of creatives and go-getters, and am influenced by the many subcultures that I grew up around (the hardcore punk scene, graffiti artists, hip-hop heads, fighting game nerds, and anime/manga otaku). What defines me however, is my love of new tech, creating future-facing yet human-centered designs, and a strong sense of empathy that can only come about from existing in multiple worlds at once as both a multi-cultural person and someone with a bleeding disorder - Hemophilia A.

#### ***Sydney Ignasiak***

Sydney Ignasiak, a recent graduate of Portola High School, will be attending The University of San Diego as a member of their Honors program in the fall. Not only is she a great student, but she is also an avid golfer and an active member of her community. Sydney relocated to California from Indiana for her senior year due to her mother's job transfer. Demonstrating resilience, she jumped right in and fully embraced this.

**William Martinez-Cerezo**

Hello, my name is William Martinez-Cerezo, and I attend Cal Poly Pomona majoring in civil engineering and minoring in mathematics. At the age of eight years, I was diagnosed with Von Willebrand disease. Later, with the help of the Hemophilia Foundation of Southern California my family has been able to learn an extensive amount about this disease that has allowed me to live a close to normal life. I remember growing up not being able to participate in certain sports due to my disease but was guided to different activities such as academics and other sports that didn't have hard contact. Through this guidance and my family's was where I was able to find my interest in engineering and technology and therefore explore more on. Now at 23 I am one year away from finishing my undergraduate degree and hope to contribute to my community through engineering and health services.

**Vicky Michua**

Vicky Michua is pursuing her Associate in Sciences in American Sign Language at Mt. San Antonio Community College and wants others to know that it is never too late to continue your education to help others.

**Yatzared Michua**

Hello, my name is Yatzared Michua I have been part of HFSC since 2017. I am beyond grateful to have received this scholarship as it will help me continue my education. I am forever grateful for all the work the foundation has done for my family and me in welcoming us in when my sister and I got diagnosed. Thank you to the HFSC for considering my application.

**2023 DR. EARL JAMES FAHRINGER ARTS SCHOLARSHIP**

Due to the extreme generosity of the late Dr. Earl James Fahringer, HFSC is thrilled to have a scholarship fund that is awarded to students pursuing a major in music, arts, dance, or drama.

**Leonardo DaMora**

Leonardo DaMora was born in Argentina to Italian parents and was born with severe hemophilia A. At three months old, he was diagnosed after a brain bleed that caused him to lose his vision. Leonardo moved to Los Angeles as a child, and began his love for music in Kindergarten. After high school, Leonardo has been attending Pasadena City College in the music program, and hopes to eventually pursue a doctorate in music composition.

**Andrea Puente**

Hello! My name is Andrea Michelle Puente, I am 19 years old and diagnosed with Platelet Pool Storage disorder. I aspire to be a Freelance Illustrator, I am currently attending Pacific Northwest College of Art going into my Junior year and majoring in Illustration. The money awarded through this scholarship will go towards my tuition as well as buying the supplies and materials needed for my classes.

**2023 VICTORIA MENDOZA PEREZ MEMORIAL HEALTHCARE SCHOLARSHIP**

This scholarship was created in memory of Victoria Mendoza Perez who believed in giving back to one's community and stressed the value of education. It is in this spirit that we award this scholarship to those who are pursuing a career in healthcare.

**Hayk Beglaryan**

Hayk Beglaryan is pursuing a LVN license at CES College and hopes to continue his education in pursuit of a career as a Nurse Practitioner.

**Lena Cook**

As a passionate third-year Doctor of Physical Therapy student, I am dedicated to improving the lives of individuals with bleeding disorders while advocating for women's health. Fueled by my personal journey of overcoming challenges to receive adequate care for my own bleeding disorder, I am driven to pursue a career in healthcare, aiming to deliver equitable and comprehensive care to underserved communities.

**If you are interested in donating to any of our scholarship funds, please contact Michele Warner, Director of Development, at [mwarner@hemosocal.org](mailto:mwarner@hemosocal.org).**

**Please look for our 2024 Scholarship Applications which will be posted on the HFSC website in March 2024!**



# 2023 CAMP BLOOD BROTHERS AND SISTERS

From July 16-21, HFSC Campers enjoyed a spectacular week at The Painted Turtle for Camp Blood Brothers and Sisters. It was a week of fun, making new friends, meeting old friends, and spending time as a community. From challenging themselves on the ropes course, horseback riding, fishing, learning archery, and competing in camp games, campers were never bored!

Our Camp awards campers each year who complete or attempt infusion, as it is so important for them to learn. Our awards include:

**Big Stick Award:** Independent completion of peripheral self-infusion from start to finish

**All Access Award:** Independent completion of port access and infusion OR subcutaneous self-infusion

**Big Courage Award:** Attempted self-infusion

**Stick-2-It Award:** Received Big Stick Award in the past, has not been infusing independently outside of camp, but was independent with infusion again while at camp

We are so proud of everyone who won an award at Camp this year!

Our Executive Director, Rigo Garcia, attended Camp for the first time this year and was blown away by the facilities, staff, and camp activities our community gets to enjoy. One of his favorite memories was having his face and hair painted for the Silly Olympics at the end of Camp.

Finally, thank you to everyone who raised funds at our walk in 2022 to ensure our campers could enjoy camp this summer. This year's Walk is being held on Saturday, November 4 at The Meadows at Whittier Narrows Park. If you are interested in creating a Walk Team or donating, please scan the QR code on the next page!

We are so thrilled every year for the opportunity to partner with The Painted Turtle to bring everlasting change and impact to our kids with rare inheritable bleeding disorders. For more information about camp, eligibility, and how to volunteer, please visit: [www.thepaintedturtle.org](http://www.thepaintedturtle.org)



## THANK YOU TO OUR CAMP BLOOD BROTHERS AND SISTERS SPONSORS!

### CABIN



### ARCHERY



### CAMP







**Unite**  
for Bleeding Disorders

# SUPER HEMO WALK


HFSC'S UNITE FOR BLEEDING DISORDERS WALK  
 NOVEMBER 4, 2023 • 10AM-2PM  
 WHITTIER NARROWS RECREATIONAL PARK

COME DRESSED AS YOUR FAVORITE SUPER HERO!  
 REGISTER TODAY FOR OUR LARGEST FUNDRAISER OF THE YEAR, IN SUPPORT OF  
 ADVOCACY AND ACCESS TO CARE, EDUCATIONAL AND SUPPORT PROGRAMS, RESEARCH,  
 AND CAMP BLOOD BROTHERS & SISTERS!  
[UNITEFORBLEEDINGDISORDERS.ORG/EVENT/SOCAL](http://UNITEFORBLEEDINGDISORDERS.ORG/EVENT/SOCAL)









**NOVEMBER 4, 2023**

The Meadows at  
Whittier Narrows

751 S. Santa Anita Avenue  
South El Monte, CA 91733

## "SUPERHERO" FUNDRAISING INCENTIVES



**\$25**

Earn your official 2023  
Unite for Bleeding Disorders Event T-Shirt!

Every walker who raises **\$25** or more  
will receive the 2023 collectible shirt!



Sunglasses and  
Window Cling

**\$250**



Koozie\*\*

**\$500**

\*\*Every walker who raises \$500 or more  
also becomes part of the Factor Club  
and receives an exclusive finishers medal!



Unite Hat and  
HFSC Aluminum Bottle

**\$1000**



Rolling Cooler and VIP Tent\*\*\*

**\$2500**

\*\*\*Every walker who raises \$2500 or more  
will receive an exclusive VIP tent on walk day!



**Register Today!**

Gifts are not cumulative; only one item is awarded to each fundraiser, based on total funds raised by one month post the event.

# HFSC 2023 COMMUNITY DINNERS

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## RIVERSIDE

07.27.23

On July 27, HFSC and Spark Therapeutics hosted a dinner at Palenque by Mezcal in Riverside for the bleeding disorders community. Guillermo Campillo presented on Gene Therapy, including understanding basics of genetics, reviewing gene therapy research, history, and challenges, and considering the potential of gene therapy and its applications for those with hemophilia. Thank you to Guillermo for presenting, and to Spark Therapeutics for sponsoring the dinner!



## HUNTINGTON BEACH

08.31.23

On August 31, HFSC and Sanofi hosted a Women's Community Dinner at Solita Tacos in Huntington Beach. The ladies learned about telling their story by creating a personal and compelling message, and how this message can be crafted to assist in advocacy efforts, whether in personal or medical situations. Thank you to Cynthia Chavez for presenting to our community members and to Sanofi for generously sponsoring the dinner!



## LANCASTER

09.21.23

On September 21, HFSC and Bayer hosted a community dinner at Gino's Italian Restaurant in Lancaster. The topic for the evening's discussion was "Guiding a Young Person with Hemophilia to Independence," and was presented by Erika Bocanegra. The presentation offered tips and resources for community members as they move responsibility for bleeding disorders care (such as making medical appointments and ordering medication), from the parent or caregiver to the young adult who is beginning their transition to adulthood. This critical information sparked many conversations among the participants that will help them ease the transition from parent to child. Thank you to Bayer for your sponsorship and to Erika for speaking!



## SIMI VALLEY

09.28.23

On September 28, HFSC and CSL Behring hosted a dinner for our community members at Viva la Pasta! in Simi Valley. The topic presented by Krissy Miller was on "Caregivers: Make Yourself a Priority," where she shared her compelling story about living through traumatic events related to her son's diagnosis with a bleeding disorder, and how she managed the stress of being a caregiver in the aftermath. Krissy shared pointers on small things caregivers can do to take a break from the stress throughout the day so they are better able to manage the stress and be more equipped to care for their loved one. Thank you so much to Krissy for coming out to speak, and to CSL Behring for their sponsorship!



# SHAKA SURF FEST & BEACH DAY

On September 23, HFSC community members gathered at Santa Monica Beach for the Shaka Surf Fest and Beach Day for a day filled with sun, surf, and unforgettable memories. Our community members had an absolute blast, enjoying the beautiful day at the beach, catching up with old friends, and making new ones. Surfing lessons were provided by the Aqua Surf team who took kids and adults into the waves and coached them on how to paddle and pop up. Thank you to Dr. Shawn Whelan for his support over the years for the surfing event, and for speaking to our community members on the importance of getting back up and trying again, going with the flow, and enjoying the ride. Dr. Whelan's motivational words set the tone for an amazing day!

Thank you to all our sponsors for supporting Shaka Surf Fest! Thank you to Bayer, CSL Behring, Novo Nordisk, Sanofi, and Takeda for your generous support, and to InfuCare for sponsoring a delicious lunch, and a shout out to Optum for providing snacks and water.



## OUR VISION: A WORLD WHERE NO LIFE IS LIMITED BY GENETIC DISEASE



Learn about gene therapy research for hemophilia.



Interested in enrolling in a Spark-sponsored hemophilia gene therapy clinical trial?



Want to know more about gene therapy clinical trials?

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**Discover more about gene therapy research**





## MY DECIDING FACTOR:

*Making time for what matters most.*

**vonvendi**  
[von Willebrand factor  
(Recombinant)]

**Erica**

VONVENDI Use: On-Demand & Surgery

- VONVENDI® is the **first and only treatment approved for routine use (prophylaxis)** in adults with severe Type 3 VWD who previously received on-demand therapy
- VONVENDI is **also approved for on-demand and surgical bleed management** in adults with all types of VWD
- VONVENDI **replaces VWF** (the main issue behind VWD), and **may be used with or without recombinant factor VIII** as instructed by your healthcare provider



**Are you ready to ask about VONVENDI for your VWD? Visit [VONVENDI.com](http://VONVENDI.com) to learn more, and talk to your healthcare provider.**

VWD=von Willebrand disease; VWF=von Willebrand factor.

### **VONVENDI [von Willebrand factor (Recombinant)] Important Information**

#### **What is VONVENDI?**

VONVENDI is used in adults (age 18 years and older) diagnosed with von Willebrand disease to:

- treat and control bleeding episodes
- prevent excessive bleeding during and after surgery
- reduce the number of bleeding episodes when used regularly (prophylaxis) in adults with severe Type 3 von Willebrand disease receiving on-demand therapy

#### **Detailed Important Risk Information**

##### **Who should not use VONVENDI?**

You should not use VONVENDI if you:

- Are allergic to any ingredients in VONVENDI.
- Are allergic to mice or hamsters.

Tell your healthcare provider if you are pregnant or breastfeeding because VONVENDI may not be right for you.

##### **How should I use VONVENDI?**

Your first dose of VONVENDI for each bleeding episode may be administered with a recombinant factor VIII as instructed by your healthcare provider.

Your healthcare provider will instruct you whether additional doses of VONVENDI with or without recombinant factor VIII are needed.

##### **What should I tell my healthcare provider before I use VONVENDI?**

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.

- Are breastfeeding. It is not known if VONVENDI passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if VONVENDI can harm your unborn baby.
- Have been told that you have inhibitors to von Willebrand factor (because VONVENDI may not work for you).
- Have been told that you have inhibitors to blood coagulation factor VIII.

##### **What else should I know about VONVENDI and von Willebrand Disease?**

Your body can form inhibitors to von Willebrand factor or factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop VONVENDI or factor VIII from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to von Willebrand factor or factor VIII.

##### **What are the possible side effects of VONVENDI?**

You can have an allergic reaction to VONVENDI.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Side effects that have been reported with VONVENDI include: headache, nausea, vomiting, tingling or burning at infusion site, chest discomfort, dizziness, joint pain, joint injury, increased liver enzyme level in blood, hot flashes, itching, high blood pressure, muscle twitching, unusual taste, blood clots and increased heart rate.

Tell your healthcare provider about any side effects that bother you or do not go away.

**You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.**

**Please see the VONVENDI Consumer Brief Summary on the following page and talk to your healthcare provider.**



## Important facts about VONVENDI® [von Willebrand factor (Recombinant)]

This leaflet summarizes important information about VONVENDI. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider.



### What is VONVENDI?

VONVENDI is a recombinant medicine used to replace low levels or not properly working von Willebrand factor in people with von Willebrand disease. Von Willebrand disease is an inherited bleeding disorder in which blood does not clot normally.

VONVENDI is used in adults (age 18 years and older) diagnosed with von Willebrand disease to:

- Treat and control bleeding episodes
- Prevent excessive bleeding during and after surgery
- Reduce the number of bleeding episodes when used regularly (prophylaxis) in adults with severe Type 3 von Willebrand disease receiving on-demand therapy.

### Who should not use VONVENDI?

You should not use VONVENDI if you:

- Are allergic to any ingredients in VONVENDI.
- Are allergic to mice or hamsters.

Tell your healthcare provider if you are pregnant or breastfeeding because VONVENDI may not be right for you.

### What should I tell my doctor before I use VONVENDI?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if VONVENDI passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if VONVENDI can harm your unborn baby.
- Have been told that you have inhibitors to von Willebrand factor (because VONVENDI may not work for you).
- Have been told that you have inhibitors to blood coagulation factor VIII.

### What is the most important information I need to know about VONVENDI?

VONVENDI can cause blood clots particularly in patients with known risk factors for blood clots. Discuss this risk with your healthcare provider.

You can have allergic reactions to VONVENDI. Symptoms may include generalized itching; rash or hives; rapid swelling of the skin or mucous membranes; chest pain or tightness; tightness of the throat; low blood pressure; shock; drowsiness; nausea; vomiting; tingling, prickling, burning, or numbness of the skin; restlessness; wheezing and/or difficulty breathing; lightheadedness; dizziness; or fainting. If symptoms occur, stop using VONVENDI immediately and get emergency treatment right away.

Your body can form inhibitors to von Willebrand factor or factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, they may stop VONVENDI or FVIII from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to von Willebrand factor or factor VIII.

### What are the possible side effects of VONVENDI?

Side effects that have been reported with VONVENDI include: headache, nausea, vomiting, tingling or burning at infusion site, chest discomfort, dizziness, joint pain, joint injury, increased liver enzyme level in blood, hot flashes, itching, high blood pressure, muscle twitching, unusual taste, blood clots and increased heart rate. These are not all the possible side effects with VONVENDI. You can ask your healthcare provider for information that is written for healthcare professionals.

Tell your healthcare provider about any side effects that bother you or do not go away.

### What else should I know about VONVENDI and von Willebrand Disease?

Consult with your healthcare provider to make sure you are carefully monitored with blood tests to measure levels of von Willebrand factor and factor VIII so they are right for you.

You may infuse VONVENDI at a hemophilia treatment center (HTC), at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or HTC. Many people with von Willebrand disease learn to infuse VONVENDI by themselves or with the help of a family member.

Call your healthcare provider right away if your bleeding does not stop after taking VONVENDI.

Medicines are sometimes prescribed for purposes other than those listed here. Do not use VONVENDI for a condition for which it is not prescribed. Do not share VONVENDI with other people, even if they have the same symptoms that you have.

**The risk information provided here is not comprehensive. To learn more, talk with your healthcare provider or pharmacist about Vonvendi. The FDA approved product labeling can be found at [https://www.shirecontent.com/PI/PDFs/VONVENDI\\_USA\\_ENG.pdf](https://www.shirecontent.com/PI/PDFs/VONVENDI_USA_ENG.pdf) or call 1-877-TAKEDA-7 (1-877-825-3327).**

**You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.**

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US-VON-0657v1.0 04/22



# emPOWERment WEBINAR SERIES

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07.12.23

On July 12, HFSC community members were led in a discussion about Advocating in Emergencies, by Lena Volland of the National Bleeding Disorders Foundation (NBDF). Lena discussed knowing the “3 D’s” of your bleeding disorder – the Disorder, the Drug, and the Dose for medications. She also recommended wearing a Medical Alert ID in the event you are not able to explain your or your family member’s disorder. Other ways to prep for emergencies include obtaining a letter from your HTC for traveling, keeping stocked first aid kits in the car and home, educating friends and family members on your disorder and what medications are taken, as well as longer term planning by seeing your bleeding disorder treatment team often, logging bleeds and symptoms, checking medications against expiration date, and having medication refilled before they are out. It is also a good idea to talk to your hematology team to find out reasons to go to the ER (such as uncontrolled bleeding or unconsciousness, and any time there is a head or neck injury), which ER the treatment team prefers, and if the recommended ER stocks your medications. Finally, in any emergency, it’s important to remember to ask for help from family and friends who can support and advocate for you/your family members as well as ask clarifying questions like “Can you please spell that for us?” to ensure that information is correctly passed along. Finally, when in doubt, please reach out to your HTC or hematologist in an emergency and they will help instruct you on the best course of action. Thank you to Lena and NBDF for providing this excellent information!

08.23.23

On August 23, CJ Cook of the Inland Counties Regional Center presented on how to prepare for disasters. In the days leading up to the webinar, Southern California was faced with several potential emergency situations including Hurricane Hilary and an earthquake, providing a great reminder to our community disasters can be just around the corner, and preparation prior to an emergency is key to successfully navigating it. CJ encouraged families to create a Disaster Plan, organizing an emergency bag for every family member – including pets – with food, water, and supplies, having extra medication on hand, and designating a meeting spot should the family be separated when a disaster hits. He also recommended signing up for local emergency alerts and planned outage notifications to help remain in the loop should something happen. The webinar ended with a prize wheel giveaway of an Emergency Kit. Thank you so much to CJ for all his insight and expertise!

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## BRO EDUCATIONAL DINNER & DODGER GAME

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On August 12, the Bleeders Reaching Out (BRO) Group met for an educational dinner at Traxx Restaurant where they heard Dr. Mike Zolo present on kinesiology taping of the shoulder, elbow, wrist, neck, low back, knee, and ankle, and how to do so if there is an acute injury. He also showed how to reduce swelling and improve range of motion through taping to improve overall stability and reduce pain. After the dinner, the BRO group rode the tram to Dodger Stadium where they caught the Dodgers versus Rockies game. Thank you to Octapharma for sponsoring this awesome educational event!



# MEDICAL SPOTLIGHT

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## NIH designates people with disabilities as a population with health disparities

Today, Eliseo J. Pérez-Stable, M.D., director of the National Institute on Minority Health and Health Disparities (NIMHD), designated people with disabilities as a population with health disparities for research supported by the National Institutes of Health. The decision was made in consultation with Robert Otto Valdez, Ph.D., the director of the Agency for Healthcare Research and Quality, after careful consideration of a report delivered by an NIMHD advisory council, input from the disability community and a review of the science and evidence. A report issued in December 2022 by the Advisory Committee to the (NIH) Director (ACD), informed by the work of the Subgroup on Individuals with Disabilities, explored similar issues faced by people with disabilities. The designation is one of several steps NIH is taking to address health disparities faced by people with disabilities and ensure their representation in NIH research.

"This designation recognizes the importance and need for research advances to improve our understanding of the complexities leading to disparate health outcomes and multilevel interventions," said Dr. Pérez-Stable. "Toward this effort, NIMHD and other NIH institutes launched a new research program to better understand the health disparities faced by people with disabilities who are also part of other populations designated as having health disparities."

NIMHD is the lead NIH institute on monitoring minority health and health disparities research. Designated populations experience significant disparities in their rates of illness, morbidity, mortality and survival, driven by social disadvantage, compared to the health status of the general population. A health disparity designation helps to encourage research specific to the health issues and unmet health needs of these populations. Other NIH-designated populations with health disparities include racial and ethnic minority groups, people with lower socioeconomic status, underserved rural communities and sexual and gender minority groups.

"Access to quality health care is a basic human right. It is unacceptable that in 2023, every person in the United States of America does not have that access," said HHS Secretary Xavier Becerra. "Research to understand the barriers and unmet needs faced by people with disabilities, and to develop effective interventions to address them, is needed. This designation will help to improve access to healthcare and health outcomes for all people."

People with disabilities often experience a wide and varying range of health conditions leading to poorer health and shorter lifespan. In addition, discrimination, inequality and exclusionary structural practices, programs and policies inhibit access to timely and comprehensive health care, which further results in poorer health outcomes. People with disabilities who also belong to one or more other populations with health disparities fare even worse.

Today, NIH also issued a notice of funding opportunity calling for research applications focused on novel and innovative approaches and interventions that address the intersecting impact of disability, race and ethnicity, and socioeconomic status on healthcare access and health outcomes.

"To the disability community, we hear you and thank you for sharing your lived experiences with NIH," said Acting NIH Director Lawrence A. Tabak, D.D.S., Ph.D. "This designation marks an important step in an agency-wide effort to advance health equity for people with disabilities which also includes updating the NIH mission statement to accurately reflect our goal of turning scientific discoveries into better health for all, including people with disabilities."

NIH recently issued a Request for Information (RFI) inviting feedback on a proposed update to the NIH mission statement following the recommendations by the ACD informed by the work of the Subgroup on Individuals with Disabilities. The ACD issued a report in December 2022 that included the recommendation to update the NIH mission statement, particularly the phrase "reduce [...] disability." NIH leadership and subject matter experts evaluated the current mission statement and proposed a revised mission statement. The RFI is open through Nov. 24, 2023.

"The Administration for Community Living commends NIH for taking these critical steps to begin addressing the significant and longstanding health disparities experienced by people with disabilities," said Alison Barkoff, who leads ACL and serves as the advisor to the HHS Secretary on disability policy. "Today's decision complements other important actions HHS has taken to advance equity for disabled people, including the proposed update to the regulations prohibiting disability discrimination by recipients of HHS funding."



## Hemophilia Foundation of Southern California

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If you would like a copy of this newsletter in Spanish, please contact the HFSC office at 626-765-6656 or [info@hemosocal.org](mailto:info@hemosocal.org), and we would be happy to send one to you!

**¡Si desea una copia de este boletín de noticias en español, por favor póngase en contacto con la oficina de HFSC al 626-765-6656 o [info@hemosocal.org](mailto:info@hemosocal.org)!**



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### *Save the Date*

#### 2023 SNOWFLAKE DINNERS:

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NOVEMBER 30: MONTEREY PARK  
DECEMBER 3: BAKERSFIELD  
DECEMBER 4: SANTA BARBARA  
DECEMBER 5: BURBANK  
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CUCAMONGA  
DECEMBER 7: LANCASTER  
DECEMBER 13: ORANGE COUNTY



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