

HEMOPHILIACTION

A PUBLICATION OF THE HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA

VOLUME 18 | ISSUE 4 | FALL | 2022



2022 FAMILIA DE SANGRE

La Hemophilia Foundation of Southern California, la Hemophilia Foundation of Northern California, Central California Hemophilia Foundation, y la Hemophilia Association of San Diego County se emocionaron al albergar la 6ª. Conferencia Anual Familia de Sangre en septiembre. De vuelta en persona después de dos años, el evento tuvo lugar en Anaheim, CA, con más de 600 personas que se unieron para un fin de semana de educación, empoderamiento y apoyo.

La conferencia comenzó el viernes por la noche con una ceremonia de apertura para todos los asistentes seguido con exposiciones con 26 expositores. Las familias aprendieron sobre nuevos productos, recibieron información sobre diferentes recursos y pudieron conectarse con nuevos y viejos amigos. La noche terminó con un animado concierto del Mariachi Arcoíris de Los Ángeles para que las familias disfrutaran de buena música y bailaran toda la noche.

Los asistentes pudieron elegir entre una selección de presentaciones de desayuno el sábado por la mañana, antes de continuar hacia la sala de exposiciones y las sesiones educativa. Las sesiones incluyeron nuevas opciones de tratamiento, terapia génica, inmigración, así como pistas para mujeres, hombres y adolescentes. El domingo, la conferencia concluyó con una presentación del patrocinador de titanio Takeda y las palabras de clausura del Comité de Familia de Sangre. (continued on page 15)

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Maria Perez, in memory of Victoria Mendoza Perez
John & Suzanne Sisco & Family, in memory of Gerald Campbell Maclellan

2023 **CALENDAR**

Industry Forum: Pipeline Products (Virtual) January 18

Industry Forum Pasadena City College | Pasadena, CA January 21

EmPOWERment Webinar Series (Virtual)
February 8

Washington Days (NHF) Washington, D.C. March 8 - 10

Women's Retreat
Marriott Irvine Spectrum | Irvine, CA
March 18 - 19

EmPOWERment Webinar Series (Virtual) March 29

HEMOPHILIACTION

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A LETTER FROM THE BOARD PRESIDENT

A heartfelt thank you to all of you for your support of HFSC's 14th Annual Unite for Bleeding Disorders HEMO Hallo-Walk, where more than 350 attendees came out to the LA Coliseum on October 29, in support of those with bleeding disorders in Southern California.

With your help, we raised over \$167,000 in support of Camp Blood Brothers & Sisters, educational programs, emergency financial assistance, scholarships, and research. Thank you!! If you haven't yet donated and would like to do so, please visit www.uniteforbleedingdisorders.org/event/socal.

As I wish you all happy holidays, recognizing the holiday season is for many a time for celebration, I also realize that for families

struggling financially, the extra expense of the holidays can be a concern. HFSC's Emergency Financial Assistance (EFA) Program helps bridge the gap by providing temporary financial assistance to help with needs like shelter, transportation, and utility bills. If you are in need of assistance at this time, please reach out to the Foundation or visit www.hemosocal.org/emergency-resources for more information. If you would like to donate to the EFA program, please visit www.hemosocal.org/donate.

Happy holidays, and 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 Kelly, MBA

A LETTER FROM THE EXECUTIVE DIRECTOR

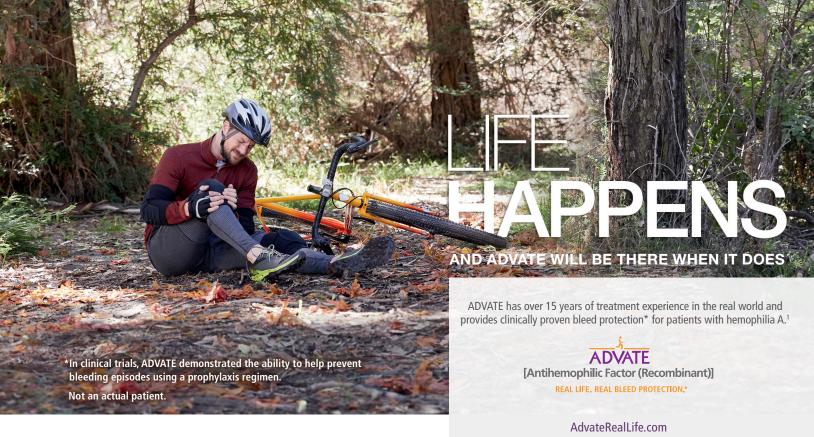
What an amazing Fall season we have had! From our Camp Blood Brothers and Sisters to our Familia de Sangre Conference, we were so happy to see so many people attending our events. The team is working hard to make sure all our events are safe, and we thank you for trusting us with coming back to enjoy our in-person events.

The summer was a busy time for the Foundation. I started as the Executive Director and hit the ground running with not only some of our major events, but many small events as well where I was able to meet many of you in person. I have worked in public health for 20 years and never had I received such an amazing welcome. THANK YOU! My promise to you is I will do what I can to make sure we continue to provide top notch programming, amazing speakers and conferences, and resources for our community.



During the summer, in addition to planning programming, the team and I attended the Bleeding Disorders Conference held in Houston, TX. We have also attended other conferences and trainings to make sure we stay up to date on new medication, changes in healthcare coverage, and new resources.

As we transition from our Summer/Fall events and into the Winter, I want to wish you all Happy Holidays! This time of year always reminds us to be thankful for all we have and for all those around us. The Hemophilia Foundation of Southern California is here for you and we can't wait to share all the exciting programming and changes coming in 2023. - Rigo Garcia



Prophylaxis with ADVATE prevented bleeds1

The ability of ADVATE to treat or prevent bleeds was evaluated in a clinical study using a standard prophylaxis, pharmacokinetic driven prophylaxis, and on-demand treatment.

53 previously treated patients (PTPs) with severe to moderately severe hemophilia A were analyzed. For the first 6 months of the study, patients received on-demand treatment. For the following 12 months of the study, patients received either standard prophylaxis every 48 hours or a pharmacokinetic-driven prophylaxis every 72 hours. The primary goal of the study was to compare annual bleeding rates between those receiving prophylaxis treatment and those receiving treatment on-demand. The number of bleeds per year for the 2 prophylaxis regimens were comparable.

- Those patients experienced a median of 1 overall bleed per year on either prophylaxis treatment vs 44 overall bleeds per year with on-demand treatment.† This represented a 98% reduction in overall bleeds per year.
- Zero bleeds were reported in 42% of patients (22 out of 53 patients) during 12 months on prophylaxis

†Median is the middle number in a group of numbers arranged from lowest to highest.

ADVATE Important Information What is ADVATE?

- ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia).
- ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A. Your healthcare provider (HCP) may give you ADVATE when you have surgery.
- ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION Who should not use ADVATE?

Do not use ADVATE if you:

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

Tell your HCP if you are pregnant or breastfeeding because ADVATE may not be right for you.

What should I tell my HCP before using ADVATE?

Tell your HCP 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 bothal remedice.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADVATE passes into your milk and if it can harm your baby.

Reference: 1. ADVATE Prescribing Information.

What should I tell my HCP before using ADVATE? (continued)

- Are or become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What important information do I need to know about ADVATE?

- You can have an allergic reaction to ADVATE. Call your HCP 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.
- Do not attempt to infuse yourself with ADVATE unless you have been taught by your HCP or hemophilia center.

What else should I know about ADVATE and Hemophilia A?

 Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE from working properly. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

What are possible side effects of ADVATE?

Side effects that have been reported with ADVATE include: cough, headache, joint
swelling/aching, sore throat, fever, itching, unusual taste, dizziness, hematoma,
abdominal pain, hot flashes, swelling of legs, diarrhea, chills, runny nose/
congestion, nausea/vomiting, sweating, and rash. Tell your HCP about any side
effects that bother you or do not go away or if your bleeding does not stop after
taking ADVATE.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see Important Facts about ADVATE on the following page and discuss with your HCP.

For Full Prescribing Information, visit www.ADVATE.com.





Important facts about

ADVATE [Antihemophilic Factor (Recombinant)]

This leaflet summarizes important information about ADVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADVATE. If you have any questions after reading this, ask your healthcare provider.

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

Do not attempt to do an infusion to yourself 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 infusing ADVATE so that your treatment will work best for you.

What is ADVATE?

ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia). The product does not contain plasma or albumin. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A.

Your healthcare provider may give you ADVATE when you have surgery. ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

Who should not use ADVATE?

You should not use ADVATE if you:

- · Are allergic to mice or hamsters.
- · Are allergic to any ingredients in ADVATE.

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

How should I use ADVATE?

ADVATE is given directly into the bloodstream.

You may infuse ADVATE at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADVATE to use based on your weight, the severity of your hemophilia A, and where you are bleeding.

You may have to have blood tests done after getting ADVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

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

What should I tell my healthcare provider before I use ADVATE?

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

What are the possible side effects of ADVATE?

You can have an allergic reaction to ADVATE.

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 ADVATE include:

headache joint swelling/aching cough sore throat itching fever unusual taste dizziness hematoma abdominal pain hot flashes swelling of legs diarrhea chills runny nose/congestion nausea/vomiting sweating rash

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

These are not all the possible side effects with ADVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADVATE and Hemophilia A?

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

Medicines are sometimes prescribed for purposes other than those listed here. Do not use ADVATE for a condition for which it is not prescribed. Do not share ADVATE 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 health care provider or pharmacist about ADVATE. The FDA-approved product labeling can be found at www.ADVATE.com or 1-877-825-3327.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

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emPOWERment WEBINAR SERIES **JULY 2022**

July 13, 2022

More than 40 community members joined HFSC virtually on July 13 for our fifth webinar in our emPOWERment Webinar Series, "Financial Wellness 101 for People with Chronic Disorders."

Financial Wellness is an important topic for everyone. Speaker Debra Jacobs, a financial coach and founder of Money Smart for Life, discussed the impact of fixed money mindsets and how changing stories around money can change one's actions. She also discussed the power of value-based spending and gave tips on how attendees could start taking steps to being financially well, no matter their income level.

Thank you, Debra, for your informative presentation, and HFA for your partnership!

emPOWERment WEBINAR SERIES **AUGUST 2022**

August 17, 2022

More than 50 community members joined HFSC virtually on August 17 for our sixth webinar in our emPOWERment Webinar Series, "Mild Matters."

Mild bleeding disorders are sometimes regarded as less serious, which is a barrier for some people when seeking diagnosis and care. Speaker Bekah Heckathorne, RN, lead nurse at the Hemophilia Treatment Center at Oregon Health and Science University, spoke about the changing landscape of mild bleeding disorders, types of mild bleeding disorders and issues patients face, how to determine if a person is having a bleeding episode, being prepared for bleeding episodes, and how to advocate for care for a mild bleeding disorder.

Thank you, Bekah, for your informative presentation, and HFA for your partnership!

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8TH ANNUAL BACK TO SCHOOL SYMPOSIUM

On August 6, 2022, HFSC hosted the 8th Annual Back to School Symposium at Pasadena City College.

Attendees were able to choose from an English or Spanish session to receive education on student rights in school and information on IEP and 504 Plans. Participants also received the newly released HFSC Back to School Manual as a reference.

The event began with a heartfelt goodbye from former Executive Director, Michelle Kim, and her introduction to HFSC's new Executive Director, Rigo Garcia. In the English session, Dr. Juliana Bloom presented on "The Basics of School Advocacy," and "Got Stress? Strategies for Anxiety and Worry." The Spanish session heard "Planes de clase: ir a la universidad con un trastorno sanguíneo," led by Annabelle Garcia from Takeda. Following was a panel including community speakers Cynthia Chavez, Enrique Arevalo, and Mauricio Reynado.

At the end of the day, students were able to choose a backpack for the school year. Thank you to all our wonderful volunteers for assisting us at this event!

Thank you, HFA, for your partnership, and thank you to our generous sponsors. Special thank you to Paul Clement for his extraordinary help in editing the Back to School Manual.









BRO MEETING: BLEEDERS REACHING OUT

On July 31, CSL Behring sponsored an event at Top Golf in Ontario, CA, with pro golfer Perry Parker presenting on overcoming stumbling blocks and living life to its fullest. Winning numerous tournaments, Perry is a national spokesperson and motivational speaker in the bleeding disorders community. He teaches people with bleeding disorders that they can achieve their dreams and be physically active just like he has been with his bleeding disorder. After his presentation, everyone went to the driving range and hit golf balls, with Perry providing proper swing lessons for all attendees. It was great to see golfers of all levels playing golf and having a wonderful afternoon with their peers. Thank you, Perry, for your inspirational presentation, and CSL for your support of this event!







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HFSC COMMUNITY DINNERS



Monterey Park Community Dinner 08.12.22

Patrocinado por Takeda.

HFSC tuvo la oportunidad de ser el anfitrión de la cena Mujeres Enlazadas en el hermoso restaurante Luminarias en la ciudad de Monterey Park, CA. Todas las madres, pacientes, cuidadoras y abuelas recibieron consejos sobre cómo empoderarse unas a las otras. Gracias a Annabelle García por la presentación y a Takeda por todo su apoyo a nuestra comunidad.



Orange County Community Dinner 08.23.22

HFSC hosted an amazing women's dinner at Maggiano's Little Italy in Costa Mesa sponsored by Octapharma!

All those in attendance received information on the different types of bleeding disorders that affect women and obtained an overall view of the available treatments. Thank you Amber Federizo and Octapharma for the valuable information and the delicious dinner!

CONGRATULATIONS TO ALL OF OUR **2022 SCHOLARS!**

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. Chris was known for his clear-headed ability to set goals and priorities and to pursue them to attainment. Many of those who knew him experienced his encouragement to set their own goals, move forward, and further develop their own potential. In keeping with his beliefs and his actions, this scholarship will be awarded to individuals who demonstrate these principles of goal-orientation and motivation. Awards of the scholarship will be based primarily upon the applicant's statements of goals and intentions as well as extracurricular involvement within his or her community.

JORDAN BURNS

Jordan Burns joined the Hemo Socal family when he was in 7th grade and learned to self-infuse with help from his Blood Brothers and Sisters at The Painted Turtle. With the encouragement of HFSC, Jordan was active in sports through high school. Jordan is pursuing his undergraduate degree in Life Science at the University of Toronto where he hopes to contribute to our search for cures for diseases.

CJ COOK

CJ Cook is the Manager of Community Engagement at Inland Counties Regional Center (IRC) and is a Doctoral candidate working toward his Doctor of Business Administration, Specialization: Homeland Security, Leadership and Policy at Northcentral University, San Diego.

LENA COOK

Lena Cook is a second year Doctor of Physical Therapy student at UCSF/SFSU. She is originally from Victorville, CA and earned her bachelor's degree from Cal Poly Pomona. After graduation, she hopes to go on to work with underserved populations like the bleeding disorders community.

JOSEPH COOK

Joseph Cook is a junior at Northern Arizona University in Flagstaff majoring in Criminal Justice with minors in Psychology and Emergency Management.

VIKESH DHEERIYA

Vikesh Dheeriya was born and raised in Palos Verdes, California. He is excited to major in Environmental Studies as an incoming freshman at the University of California, Santa Barbara.

JARETT GUILLOW

Jarett Guillow is in his second year of medical school at UC Riverside School of Medicine. He hopes to achieve his lifelong goal of becoming a doctor and to serve as a role model and mentor for the next generation of people with bleeding disorders.

MELISSA MARTINEZ CEREZO

Melissa Martinez Cerezo plans to finish her Managerial Economics degree at UC Davis this year and will then pursue a career in business.

VICKY MICHUA

Vicky Michua is continuing her study of American Sign Language Interpreting at Mt. San Antonio College this fall as she pursues her goal of helping the deaf community communicate with the hearing community.

(continued)

YATZARED MICHUA

Yatzared Michua started her first year at Mt. San Antonio College this fall and plans to pursue her dream of becoming an elementary school teacher.

ANDREW YU

Andrew Yu has severe hemophilia A and has been a part of the HFSC family since 2018. As well as working in the office for a summer, he participated in many events such as the Teen Leadership Summit and Washington Days. He is currently in his final year of undergraduate studies in mathematics at UC Berkeley and hopes to go into academia.

ADVOCACY IS IN YOUR BLOOD SCHOLARSHIP

The Advocacy is in Your Blood Scholarship was created to support students who have taken an active role in advocating for something that is important to them – whether it is legislation, a cause related to their bleeding disorder, self-advocacy, or advocating for other causes. The founder, Joshua Kim, was involved in advocating to Congress for affordable medical treatment for those affected by bleeding disorders. Joshua saw how hemophilia didn't have to restrict one's life, but only through affordable treatment.

ALBERT JIMENEZ

Albert Jimenez, who currently attends Orange Coast College, has the goal of becoming a lawyer and a dream to become a senator so that he can continue to advocate for the bleeding disorders community that has never stopped advocating for him.

CARSON KNIGHT

Carson Knight is from Solvang and has entered his final year as a political science student at Cal Poly: San Luis Obispo. He hopes to use the knowledge gained from his education in politics to ensure affordable access to medication across the country (if not the world).

VICTORIA MENDOZA PEREZ MEMORIAL SCHOLARSHIP

This scholarship was created in memory of Victoria Mendoza Perez for anyone pursuing a career in healthcare. Victoria battled breast cancer for 11 years and owed much of her success to the compassionate and holistic approach of her healthcare providers. During this time, she participated in clinical trials to help improve treatment options for other patients. She immigrated to the United States from a small Indigenous village, Zoogocho, located in the mountains of Oaxaca, Mexico. Victoria worked as a housekeeper for most of her life until the effects of chemotherapy made it too difficult to work. She believed in the importance of giving back to one's community and stressed the value of education. Although Victoria didn't have the opportunity to pursue a formal education, she supported her daughters in the pursuit of their educational goals, her recurring motto being, "Don't be like me, go to school so you can be better." It is in this spirit that we award this scholarship to applicants who are pursuing a career in healthcare.

ASRITA PRATHIGUDUPU

Asrita Prathigudupu, who began studies this fall at UC Irvine, plans to join her performing arts journey with her love for medicine. She hopes to find research programs about destignatizing mental health in teens.

ZEN SANCHEZ

Zen Sanchez, who started studying psychology and gender studies this fall at University of San Francisco, wants to be known for their advocacy for LGBTQ youth and hopes to ensure that young people are taking care of their mental wellbeing.

CAMP BLOOD BROTHERS & SISTERS AT THE PAINTED TURTLE

From July 19-23, 2022, HFSC Campers were thrilled to be back in person at the extraordinary Painted Turtle camp after three years. Many campers were first time attendees and didn't want to go home after an exhilarating week trying new things and making new friends. From challenging themselves on the ropes course, courageously performing at the talent show, and competitively encouraging each other at Silly Olympics, our campers showed resilience and fortitude. Arguably camp's biggest highlight is the recognition of our award winners: something that makes our community so unique:

Big Stick Award

Independent completion of peripheral self-infusion from start to finish

Jaime De Leon Logan Valdez
Matthew Ceja Jalen Love
Logan Dawes Mueller Suarez

Big Courage Award

Attempted self-infusion

Andrew Casas

All Access Award

Independent completion of port access and infusion OR subcutaneous self-infusion from start to finish

Logan Dawes Langston Brown Mueller Suarez

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

Earl Lee Christian Elias

WE ARE PROUD OF YOU, SAY WE ARE PROUD OF YOU!

Deep Turtle thank you to our community members who worked as staff or volunteers this summer to make this year's camp the best ever!

Thank You!

Daniel Cruz Albert Jimenez Joshua Kim Carson Knight Diego Cuellar Fiach Echandi Dr. Doris Quon Harold Crawford Huy Diep Susan Shannon

Finally, a big shout out to all of you who raised funds at our walk in 2021 to ensure our campers could enjoy camp this summer. 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

























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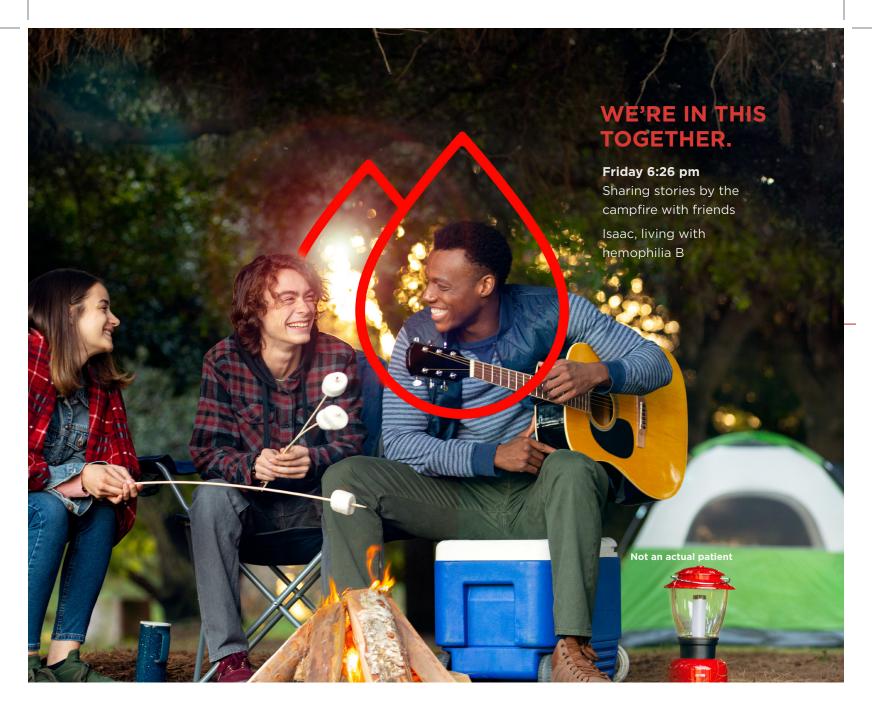


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Let's make today brilliant.

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 patients, inspired by our vision for a bleed-free world is stronger than ever.











2022 FAMILIA DE SANGRE (continued)

Este año, la conferencia estuvo encantada de dar la bienvenida a miembros de la comunidad de habla hispana de ocho estados y Puerto Rico. El Comité está muy agradecido con todos los que asistieron e hicieron la conferencia un gran éxito. Estén atentos ya que la planificación está en marcha para la 7ma Conferencia Anual de Familia de Sangre; Reserve la fecha: del 8 al 10 de septiembre de 2023.

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Happy Holidays Happy New Year

from the HFSC Staff!



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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, 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!

