

HEMOPHILIA ACTION

A PUBLICATION OF THE HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA
VOLUME 15 | ISSUE 4 | FALL | 2019



Familia de Sangre 2019



Congresswoman
Judy Chu provides
our keynote address
at HFSC's inaugural
Pain Management:
Alternative Therapies
Conference



Fifth Annual Back to
School Symposium

2020 CALENDAR OF EVENTS

- January 25 **Industry Forum**
Mt. Saint Mary's University
Los Angeles, CA
- February 12 **Mujeres Enlazadas por Sangre Dinner**
San Bernardino County
- February 13 **Community Dinner**
Ventura, CA
- February 26-28 **NHF's Washington Days**
Washington, DC
- February 29 **emPOWERment Forum and Bloody Hot Salsa Challenge**
Pickwick Gardens
Burbank, CA
- March 28-29 **Women's Retreat**
Orange County, CA
- April 17 **World Hemophilia Day**
TBD
- April 23-25 **Hemophilia Federation of American Annual Symposium**
Baltimore, MD
- May 1 **Women's Educational Forum and Von Willebrand Disease Dinner**
Knott's Berry Farm Hotel
Buena Park, CA
- May 2 **Family Info Day (Annual Meeting)**
Knott's Berry Farm Hotel
Buena Park, CA

THANK YOU, DONORS

IN MEMORY

Deborah Sazdoff in memory of Gerry Green and Family

IN HONOR

Your Cause, LLC, Trustee for Edison International
in honor of Erika Clement
Joann Cunningham in honor of Judy Mangione
Teddi Segal in honor of Milo Burke
Your Cause, LLC, Trustee for Chevron Matching Employee Funds
in honor of Rose Cardenas
Team Blaze, Inc. in honor of The Iavicoli Family
Burger Zone in honor of The Michua Family
Employees Charity Organization of Northrop Grumman in honor
of Timothy Van Loon

GENERAL DONATIONS

Jane Brady • Marjorie & Cecil Corey • Harold & Sally Crawford
Dr. E.J. Fahringer • Jeffrey and Barbara Finder
Gabriela & Joseph Griffin • Dr. James Luck
Jeff & MaryLou Wright • BJ's Restaurants Foundation Inc
Charities Aid Foundation of America
Colburn-Keenan Foundation • Deep C Digital • Gavigan and Co.
Hemophilia Federation of America • Kroger
National Hemophilia Foundation • Network for Good
The Starbucks Foundation • TWD Properties, LLC
W.M. Keck Foundation • Westmount Asset Management

BOARD OF DIRECTORS

Sandy Knight, President
Ron Staake, Treasurer
Rick Kelly, Secretary

Shin Chen, Sandy Davis, Silvia Garcia,
Wayne Guzman, Carol Jung, Kelvin Lee, Devon Rios,
Pedro Sanchez, MD

Doris Quon, MD, Medical Advisor

HFSC TEAM

Michelle Kim, Executive Director
Michele Warner, Director of Development
Laura Desai, Senior Operations Manager
Cynthia N. Chavez, Outreach Manager
Susan Hall-Hardwick, Accounting
Casey O'Brien, Events Manager

DISCLAIMERS:

The Hemophilia Foundation of Southern California (HFSC) does not endorse any particular pharmaceutical manufacturer or home care company.

PLEASE NOTE: The companies whose advertisements are listed herein have purchased this space, and are NEVER provided with member's names, addresses or any other personal details. Paid advertisements should not be interpreted as a recommendation from HFSC, nor do we accept responsibility for the accuracy of any claims made by paid advertisements. Since we do not engage in the practice of medicine, we always recommend that you consult a physician before pursuing opinions expressed in this publication are not necessarily those of the HFSC, or of its editorial staff.

Material printed in this publication may be reprinted with express prior written permission from the Executive Director.

HEMOPHILIA ACTION

is a published quarterly by

The Hemophilia Foundation of Southern California



A LETTER FROM THE BOARD PRESIDENT

This past Fall was very busy for HFSC having hosted the largest Spanish speaking bleeding disorders conference in the country with the three other CA foundations and acting as local host to the National Hemophilia Foundation (NHF) Annual Meeting in Anaheim. What a whirlwind of education, connections and support and a great opportunity for many of our members. We also held our 11th Annual Unite for Bleeding Disorders Walk where we received an outpouring of love and support and hit our highest fundraising amount to date. I am so pleased that camp is now funded, and we will be releasing the camp dates shortly! Thank you to everyone who donated to the walk! I wish you all a blessed holiday and a happy New Year! The HFSC office will be closed the last week of December for a little well deserved family time!

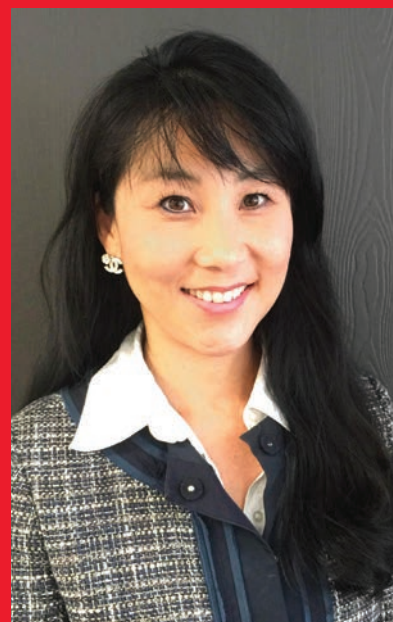
Sandy Knight, HFSC Board President

A LETTER FROM THE EXECUTIVE DIRECTOR

Our 11th Annual SoCal Unite for Bleeding Disorders Walk on November 2 was a huge success! Thank you so much to those who supported us for our biggest fundraising event of the year. With your help, we raised close to \$130,000, which is a new record for us! If you haven't yet donated and would like to do so, there is still time to donate at www.uniteforbleedingdisorders.org/event/socal. We also had a great turnout of walkers for the event, with wonderful, nostalgic music in keeping with the 80's theme and very informative vendor booths. In addition to all of the individual donors who donate to our event, we also received many donations from companies, some of which are involved in the bleeding disorders community and others who are not. We are very grateful for the support we receive from all of them. HFSC was also presented with a Certificate of Recognition by Vickere Murphy, Senior District Representative from Senator Anthony J. Portantino's office recognizing the important work that our organization does for the Bleeding Disorders Community.

Up next on the calendar are our Snowflake Festivals, which will be held at several different locations throughout Southern California. Please make sure to sign up as soon as possible as these events almost always sell out. Happy Holidays to you all!

Michelle Kim, HFSC Executive Director



VOLUNTEER SPOTLIGHT

Volunteering with HFSC has been a wonderful experience! I have enjoyed helping out at all the different events, such as the Industry Forum, the Women's Retreat, the Back to School Education Symposium, the Annual Walk, and many more. My family's experience with hemophilia inspired me to begin volunteering, and through my volunteer work, I have had the opportunity to get to know more members of the bleeding disorder community. Everyone in the organization has been so kind and welcoming to me throughout the years. Currently, I am a senior at UCLA majoring in Physiological Science. After I graduate, I hope to attend medical school and continue to help those with bleeding disorders.

WELCOME TO CALABLE,

THE GOLDEN STATE'S ACHIEVING A BETTER LIFE EXPERIENCE (ABLE) PLAN!

With the passage of the federal ABLE Act, millions of Americans with disabilities have been empowered to reach a new level of control when it comes to achieving greater financial security. ABLE accounts are a new savings option that allow individuals, who became disabled before the age of 26, to save and invest in a tax-advantaged account, without jeopardizing their ability to collect SSI.

In the past, individuals with disabilities didn't have the freedom or flexibility to keep money in their own name, receive an inheritance, or even save to purchase much needed assistive technology. That's because saving for the future meant the possibility of losing eligibility for programs like SSI or Medi-Cal.

But, with CalABLE, a world with financial freedom, independence, and a better quality of life are now at the fingertips of those with all types of disabilities. Eligible individuals throughout California, and nationwide, can sign up for a CalABLE account today and manage their money right on this website. The best part – up to \$100,000 deposited into a CalABLE account – won't affect eligibility for government programs.

This program will enhance the lives of people with disabilities, and offer peace of mind to parents, friends, and loved ones, who want to make sure these individuals will be financially secure into the future.

For more information: <https://calable.ca.gov/welcome>



Let's get together to talk about IXINITY®

“My mission in life is to work at removing barriers for people in order to help them live to their highest potential. Helping to remove barriers for those in the rare bleeding disorders community fulfills this purpose.

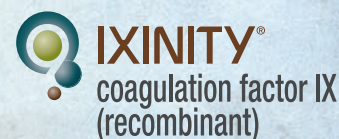
—Samuel Gbadebo, your resource for all things IXINITY



► Contact Samuel at 562-234-8531 or gbadebos@apvo.com



Aptevo BioTherapeutics LLC, Berwyn, PA 19312
IXINITY® [coagulation factor IX (recombinant)] and any and all Aptevo BioTherapeutics LLC brand, product, service and feature names, logos, and slogans are trademarks or registered trademarks of Aptevo BioTherapeutics LLC in the United States and/or other countries.
© 2017 Aptevo BioTherapeutics LLC. All rights reserved. CM-FIX-0196



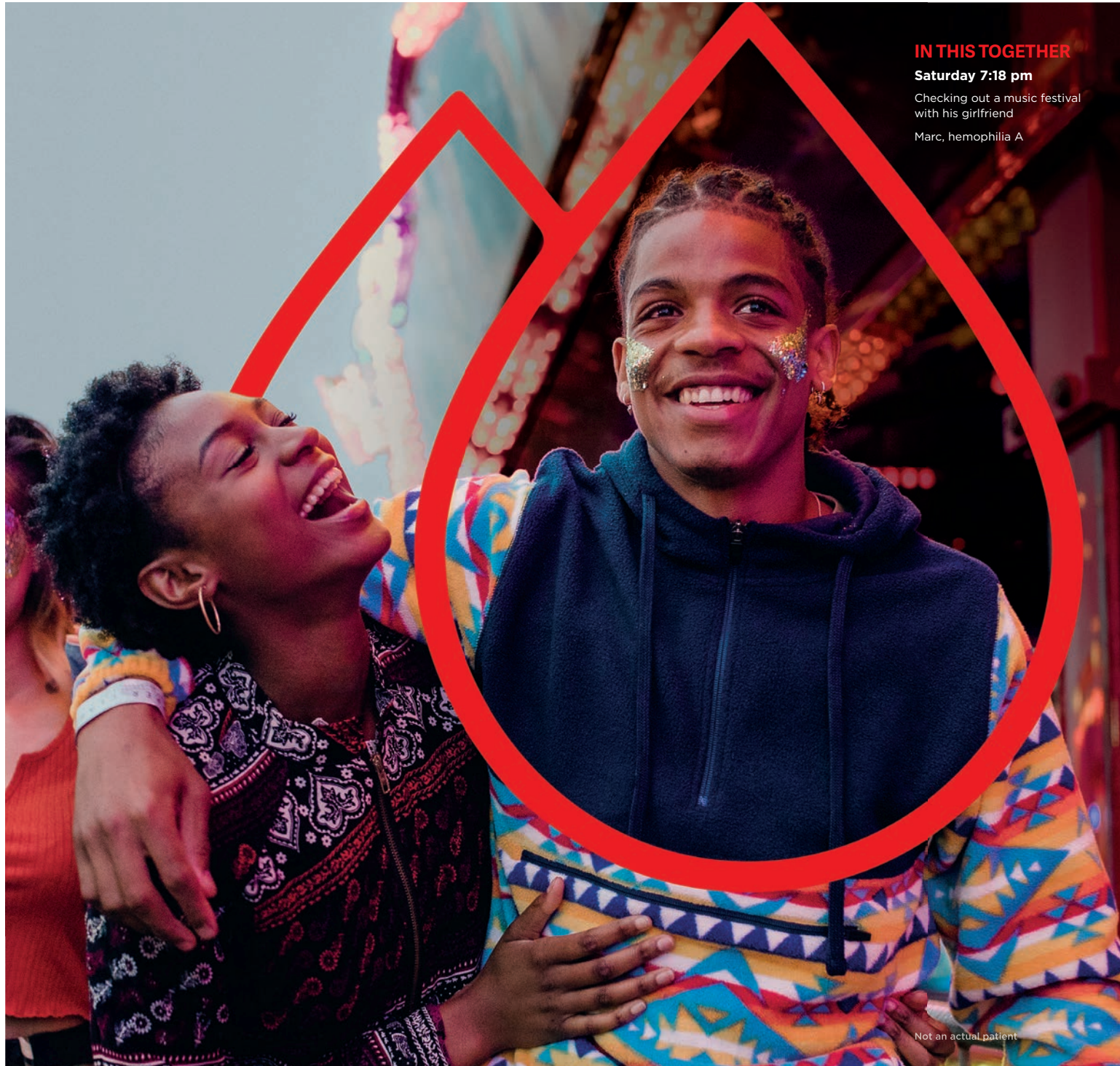


On September 9, 2019, the Hemophilia Treatment Centers (HTCs) from California, Hawaii, Nevada and Guam held a conference to discuss best practices and the future treatment of bleeding disorders. Those present included doctors, nurses, physical therapists, social workers, and representatives from the foundations. We are thankful for the work and service of our HTC medical providers and all they do to provide excellent treatment for us.

SAN BERNARDINO FAMILY DINNER



Ensuring community members are prepared for school, HFSC hosted an incredible and informational dinner learning about Individual Health/504 Plans and bleeding disorders! HFSC also distributed backpacks to all youth in attendance. Thank you to our new Inland Empire/Riverside County Community Liaison Erika Clement and Takeda for supporting this educational dinner!



IN THIS TOGETHER

Saturday 7:18 pm

Checking out a music festival
with his girlfriend

Marc, hemophilia A

Not an actual patient

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. **Let's make today brilliant.**

bleedingdisorders.com



**BAXALTA AND SHIRE ARE
NOW PART OF TAKEDA**

Copyright ©2019 Takeda Pharmaceutical Company Limited, Lexington, MA 02421. All rights reserved.
1-800-828-2088. TAKEDA and the TAKEDA logo are trademarks or registered trademarks of Takeda
Pharmaceutical Company Limited. S47420 06/19

5TH ANNUAL BACK TO SCHOOL SYMPOSIUM

On August 3, 2019, the Hemophilia Foundation of Southern California (HFSC) partnered with Children's Hospital Los Angeles (CHLA) to teach parents about federal laws that provide equal access to education. Small rap groups by grade and in English and Spanish further allowed deeper discussion, and HFSC is very thankful to our many volunteers and healthcare providers who helped facilitate these discussions.

While parents were learning about navigating the educational system, kids and teens were treated to a private screening of The Lion King sponsored by Vintage Cinemas. After sessions ended, students from Pre-K through college received free backpacks and school supplies.

Thank you to all our amazing speakers: Susana Escojido and Amalia Vega from Takeda; Dr. Gavin Roach, Director, Pediatric Hematology, UCLA; community members Anna Clark and Vicky Michua; Dr. Cathy Buranahirun, Sandra Valdovinos-Hereida, Michael Viscariello, and Octavio Zavala of CHLA; and HFSC Staff Michelle Kim and Cynthia Chavez.

If you would like the HFSC recommended accommodations list to present to your school, please email cynthia@hemosocal.org. HUGE thanks to Jenna Hansen and Elsa Raigoza from CHLA for your help!

Gratitude to Hemophilia Alliance Foundation and Takeda for your support! Thanks to our special guests Center for Inherited Blood Disorders (CIBD) and Orthopaedic Hemophilia Treatment Center (OTC).



REMEMBER HFSC Top 10 Recommendations:

1. Have an Individual Health Plan (IHP).
2. Keep factor/medicine, medical supplies or other emergency meds at school.
3. Ask to meet with the teacher or school officials prior to the start of school.
4. Bring your child to the IHP or 504 meeting when appropriately mature.
5. Allow your child to present information at the IHP/504 meeting when appropriately mature.
6. Take a friend, relative, or support person with you to your meeting if you are feeling nervous/afraid/worried.
7. Ask questions if you don't understand what the school is saying.
8. Recognize that you are an expert on your child's care and have much to contribute.
9. Do not sign any documents or plans you do not fully understand. You may take them home to review.
10. Call HFSC for help if you need it!

For great resources check out HFA's toolkit:

<https://www.hemophiliafed.org/for-patient-families/resources/toolkits/back-to-school/>

HFSC SCHOLARSHIPS 2019



Congratulations to all our scholarship recipients! We are so proud of the accomplishments of all the scholarship winners and look forward to seeing them flourish in their future academic growths!

Christopher Mark Pitkin Memorial Scholarship

Abigail Cook
Lena Cook
Mike Bindoy
Peter J Brown
Luis Cerezo
Melissa Cerezo
Cole Ford
Emily Garcia
Jarett Guillow
Erwin Luu
Vicky Michua
Jada Nuno
Cynthia Reynolds
Abel de Jesus Rosales
Rachel Wile
Andrew Yu

Dr. Earl James Fahringer Performing Arts Scholarship

Arely Michua
Isaac Puente

We're Listening



At Pfizer Hemophilia, we have always been deeply committed to you and to listening to what you have to say. Over the years, what you've shared with us has proven invaluable. The events we sponsor, the technology we develop, and the educational materials we create are all designed in response to the requests, needs, and desires of the hemophilia community.

We are grateful for having the chance to partner with you.

—Your Pfizer Hemophilia Team

GETTING IN THE GAME



It was an amazing day on Sunday, August 18, 2019 cheering on Lake Elsinore Storm, eating delicious barbecue, and gathering with our bleeding disorders family! Thank you to Florence Freedom Starting Pitcher Jesse Schrader for your encouragement with playing baseball with a bleeding disorder, and to our new Community Liaison Scott Burnett for all your help! Thank you to our event sponsor CSL Behring!



BURBANK FAMILY COMMUNITY DINNER



HFSC hosted a wonderful educational dinner on September 18, 2019 at the beautiful Castaway Restaurant in Burbank, learning about dental care and bleeding disorders! Thank you to our new community liaison Rosie Villalpando, for bringing special chocolates for all and distributing dental kits. Thank you, Takeda for the educational presentation!

 **Hemophilia Foundation
of Southern California**

INVITES YOU

5th Annual Industry Forum

- HEAR ABOUT NEW PRODUCTS FOR TREATMENT
- FREE PARKING AND CHILDCARE
- BREAKFAST AND LUNCH COMPLIMENTARY
- TICKETS TO SIX FLAGS FOLLOWING EVENT!

JANUARY 25, 2020 | 9AM-3PM

RSVP: [HTTPS://HFSCINDUSTRYFORUM2020.EVENTBRITE.COM](https://hfscindustryforum2020.eventbrite.com)

Thank you to all our sponsors!



Gracias Bayer: "Smart Games"



FAMILIA DE SANGRE

SEPTIEMBRE 6-8 | ANAHEIM, CA

Del 6 al 8 de Septiembre 2019, la Fundación de Hemofilia del Sur de California, la Fundación de Hemofilia del Norte de California, la Fundación de Hemofilia de California Central y la Asociación de Hemofilia del Condado de San Diego organizaron la 3a Conferencia Anual de la Familia de Sangre en Anaheim, California. Más de 600 miembros de la comunidad asistieron a esta conferencia de habla hispana.

La conferencia comenzó el viernes por la noche con una sesión de apertura y comentarios del miembro de la Mesa Directiva de NHF, Jorge de la Riva. A una sala de exhibiciones emocionante la gente continuo bailando toda la noche con el DJ Stephen Skillz, y los adolescentes disfrutaron de su propio programa de trivia disco organizado por GutMonkey.

El sábado comenzó con deliciosas y atractivas sesiones de desayuno organizadas por los patrocinadores Takeda, Novo Nordisk y Sanofi Genzyme. Después del desayuno, los asistentes fueron educados a través de una variedad de sesiones educativas. Las parejas compartieron luchas y triunfos en sus relaciones en una sesión de asociación emocional, y los miembros de la comunidad estaban ansiosos por asistir a la sesión de terapia génica para conocer qué ensayos se están explorando.

Las sesiones informativas también incluyeron Inmigración, Terapias emergentes, así como dos sesiones de pie sobre los conceptos básicos de la marihuana medicinal. Los adolescentes quedaron cautivados por la increíble historia de Jhon Velasco y aprendieron cómo pueden combatir el estrés a través de las luchas cotidianas, y Pat Torrey de GutMonkey los tuvo a todos activos enseñándoles sobre cómo hacer cambios en la vida. Se compartieron historias personales y se derramaron lágrimas durante el panel de Culpa sin culpa para las madres mientras se conectaban con otras mujeres de la comunidad.

La noche terminó con los participantes disfrutando de boletos para Disneylandia. La sesión de clausura del domingo por la mañana fue una presentación importante de Takeda sobre la preparación para emergencias por desastres naturales, así como un sorteo de kits de emergencia.

Gracias a nuestro Equipo de la suite Médica del Hospital de Tratamiento Ortopédico, Doris Quon, MD, Directora Médica, y Christopher Chan, NP, por pasar su fin de semana de guardia en la conferencia, y gracias a Bayer por patrocinar nuestra suite Médica. Agradecemos a nuestros profesionales médicos de habla hispana por tomarse el tiempo para presentar: Erika Bocanegra, MSW, Daisy Cortes, MD, Vanessa Salinas, MD, Pedro Sanchez, MD, Claudio Sandoval, MD y Sandra Valdovinos-Heredia, MSW, ACSW. Agradecemos a la miembro de la mesa directiva de HFSC, Carol S. Jung, Esq. por ayudar en la presentación de temas escolares como los Planes 504 y los IEP.

¡Gracias a la Federación de Hemofilia de América y a la Fundación Nacional de Hemofilia por su asociación!

Agradecemos al patrocinador de titanio Takeda y a los presentadores de su equipo educativo de habla hispana: Clemencia Casas-Byots, Susana Escojido, RN, Binh Le, BS y Amalia Vega, MPH.

Nos gustaría agradecer a nuestros patrocinadores: los patrocinadores de platino Novo Nordisk y Sanofi Genzyme; Patrocinadores de oro Bayer, CSL Behring y Genentech; Patrocinadores de plata Octapharma y Brothers Healthcare. ¡Gracias a nuestros increíbles voluntarios!

GUARDAR LE FECHA DE FDS 2020!
Septiembre 18-20, Anaheim Marriott



*Gracias a nuestro
patrocinador Titanio*



*Gracias a nuestro
patrocinadores platinos*



*Gracias a nuestro
patrocinadores de Oro*



A person's hands are holding an open brochure in the foreground. The background shows a woman in a white shirt and yellow pants walking up a wide set of stone steps. Two children are also walking up the steps. In the distance, there is a large, light-colored stone building with a prominent circular window, likely a church or historical site. The sky is clear and blue.

GO SEEK. GO EXPLORE. GO AHEAD.

Discover your sense of go. Discover HEMLIBRA®.

HEMLIBRA.com

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. HEMLIBRA may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

Please see Brief Summary of Medication Guide on following page for Important Safety Information, including **Serious Side Effects**.



HEMLIBRA
emicizumab-kxwh 150 mg/mL
injection for subcutaneous use

Medication Guide
HEMLIBRA® (hem-lee-bruh)
(emicizumab-kxwh)
injection, for subcutaneous use

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
 - confusion
 - weakness
 - swelling of arms and legs
 - yellowing of skin and eyes
 - stomach (abdomen) or back pain
 - nausea or vomiting
 - feeling sick
 - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
 - swelling in arms or legs
 - pain or redness in your arms or legs
 - shortness of breath
 - chest pain or tightness
 - fast heart rate
 - cough up blood
 - feel faint
 - headache
 - numbness in your face
 - eye pain or swelling
 - trouble seeing

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

See “What are the possible side effects of HEMLIBRA?” for more information about side effects.

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I use HEMLIBRA?

See the detailed “Instructions for Use” that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.
- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.

- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. **Do not** give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

What are the possible side effects of HEMLIBRA?

- See “What is the most important information I should know about HEMLIBRA?”

The most common side effects of HEMLIBRA include:

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C).
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

Keep HEMLIBRA and all medicines out of the reach of children.

General information about the safe and effective use of HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048

HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan
©2018 Genentech, Inc. All rights reserved.

For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised : 10/2018



© 2018 Genentech USA, Inc. All rights reserved. EMI/061818/0106a
HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan.
The HEMLIBRA logo is a trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan.
The Genentech logo is a registered trademark of Genentech, Inc.
All other trademarks are the property of their respective owners.


Genentech
A Member of the Roche Group



PAIN MANAGEMENT: ALTERNATIVE THERAPIES CONFERENCE


Over 120 people joined us on Saturday, July 13, for this inaugural and impactful conference. Congresswoman Judy Chu representing the 27th District kicked off this event with a passionate speech about the need for more resources and support for alternative therapies. Next, we dove in with Dr. Hui, Director of the UCLA Center for East West Medicine who provided a great overview of Pain Management. Next, Felicia Carbajal, ED of the Social Impact Center shared very practical information on cannabinoids for pain including high quality brands and Dr. Gretchen Badami, gave an incredibly insightful demonstration and explanation of acupuncture including how to find a good doctor! Spencer Dunn, Social Worker at CIBD, moderated a patient pain panel with members sharing some incredibly creative ways they manage pain with Harp Mann and Matt Teutimez.

Finally, the teens planned and hosted our first ever OPEN HOUSE at the office and even came under budget. An exciting day to learn about many new therapies, with pain every patient should be uniquely outfitted with their own tailored regiment and we now have more tools to put to use! Thank you to all our supporters including our partner Hemophilia Federation of America (HFA)-we are grateful for your support! Dr. Doris Quon filled in the gaps for medical issues with bleeding disorders, Linda, Paul and Erika Clement (who ran an awesome teen program), Ivan Aravelo, Quincy Nakamura, Board Members; Ron Staake and Shin Chen all helped out greatly! Thank you also to Burberry for your generous donation of 10 navy blue blazers and to our additional sponsors: Bayer, CSL Behring, Fidelis, Genentech, Novo Nordisk, Octapharma and Soleo Health.



**Children's Hospital
LOS ANGELES**


HEMOSTASIS AND
THROMBOSIS CENTER



**Children's Hospital
LOS ANGELES**

DIVISION OF
ADOLESCENT AND YOUNG
ADULT MEDICINE

Hematology-Adolescent Medicine Combined Clinic



Undiagnosed, misdiagnosed, and untreated bleeding disorders in young girls and adolescents have unique medical consequences. Early diagnosis of bleeding disorders is crucial to help prevent complications later in life. CHLA's Hematology-Adolescent Medicine combined clinic offers both hematology and adolescent reproductive health expertise in one clinic. The goal of our combined clinic is to diagnose and treat bleeding disorders and the heavy menstrual cycles that often accompany in order to enhance the safety and quality of life of our female patients.

Services We Offer

- 3x per month combined Heme/Adol clinic
- 1x per month IUD clinic
- Services for girls with heavy menstrual bleeding
- Evaluation for potential bleeding disorders
- Treatment and management for diagnosed bleeding disorders

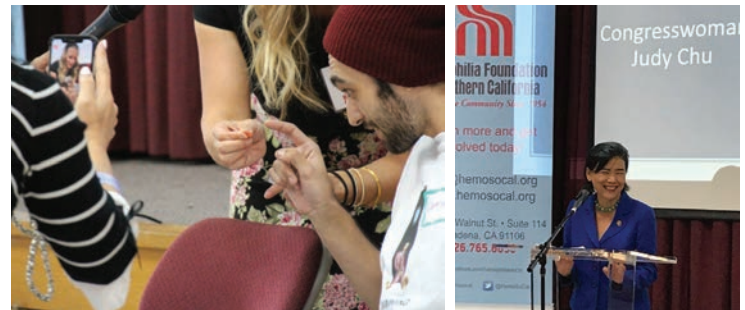
For More Information

(323) 361-4624

Meet our Team of Experts

- Julie Jaffray, MD
- Claudia Borzutzky, MD
- Jennifer Donkin, DNP(c), RN, CPNP
- Jacquelyn Keegan, MSN, RN, CPNP

- Wendy Leung, MSN, RN, CPNP
- Erin Cooper, MSN, RN, CPNP
- Sandra Valdovinos-Heredia, ACSW, MSW



WHAT WOMEN WITH BLEEDING DISORDERS NEED TO KNOW ABOUT **IRON-DEFICIENCY ANEMIA**

Too little iron may cause big problems.

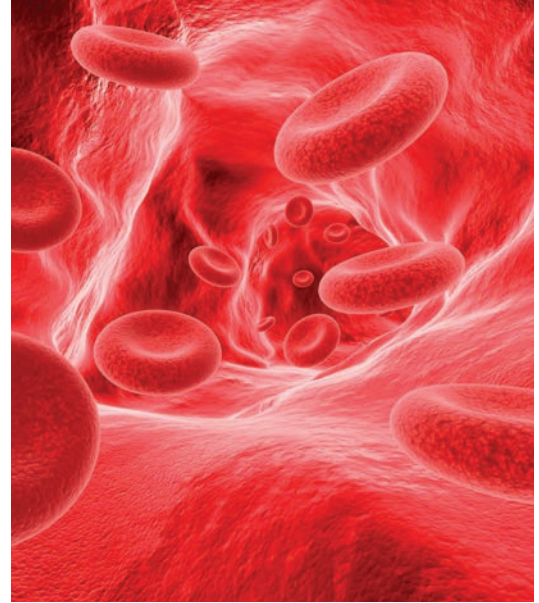
Author: Lisa Fields
Women's Bleeding Disorders

If you feel inexplicably tired, weak or dizzy, or experience headaches or nausea, you may have anemia. Women and girls with von Willebrand disease and other bleeding disorders—and many genetic carriers of bleeding disorders—are at increased risk of this condition, largely because of blood loss from heavy or prolonged menstrual bleeding. “Women with bleeding disorders are at much greater risk because they have more severe and longer duration of bleeding,” says Margaret Ragni, MD, MPH, professor of medicine in the division of hematology/oncology at the University of Pittsburgh Medical Center and director of the Hemophilia Center of Western Pennsylvania.

There are several types of anemia, including vitamin-deficiency anemia, anemia of chronic disease, aplastic anemia and sickle cell anemia. The most common form is iron-deficiency anemia, which affects about 3 million people per year in the United States—a disproportionate number of them women.

PUMPING IRON

Iron is key to the production of hemoglobin within red blood cells. Hemoglobin transports oxygen to cells, nourishing organs and tissues. When iron stores run low because of blood loss, oxygen isn't distributed well throughout the body. This is what can cause those feelings of tiredness and dizziness. You may also experience depression or anxiety, a rapid heartbeat or memory problems.



“In addition to standard tiredness and fatigue and headaches, you can have central nervous system changes—changes in cognition and understanding, mental functioning, mood and physical functioning,” Ragni says. “You can't do your daily tasks.” Another cause of low iron, and thus a risk factor for anemia, is a diet lacking in iron-rich foods. “If you don't eat meat, for example, that limits the amount of iron intake, and it may even trip you into a borderline iron deficiency,” Ragni says. Lean beef, poultry and seafood are all good sources of iron. Green, leafy vegetables, legumes and grains such as quinoa, brown rice and oatmeal are also iron-rich.

“A diet high in iron-rich foods is always a good idea, whether it's meat or plant-based foods,” says Tina Willis, RDN, a nutritionist at the Indiana Hemophilia & Thrombosis Center. “Heme iron comes from animals—meat and eggs—and is more readily absorbed by our bodies. Non-heme iron comes from plant-based sources, and that iron is a little more difficult for our bodies to absorb.”

ANEMIA AND PREGNANCY

Women who are pregnant need to be especially concerned about anemia. During pregnancy, anemia risk rises because blood volume increases to nourish the growing baby, yet iron levels remain the same. Mild anemia during pregnancy is common. “The difference for women who have von Willebrand disease or are carriers is they may have been iron-deficient before they got pregnant,” Ragni says. “That may put you in a more precarious place.”

DIAGNOSIS AND TREATMENT

If your doctor suspects you are anemic, she'll test you for iron deficiency and anemia through a simple blood test. If you have anemia, she'll probably prescribe iron supplements. “It doesn't go away overnight,” Ragni says. “It took months to get there, and it takes months to get better.”

Your doctor may also prescribe hormone treatments or medication to control heavy menstrual bleeding so you're less likely to become anemic in the future.

THE SCOOP ON IRON SUPPLEMENTS

Doctors often recommend ferrous sulfate supplements for anemia because they're the cheapest and most widely available, but they can cause constipation and other gastrointestinal woes. “I prescribe ferrous gluconate, which may be better tolerated,” says hematologist Margaret Ragni, MD, MPH. If you don't improve with iron supplementation after a month or two, you may need intravenous iron. This is also offered to the small percentage of women who can't tolerate iron supplements.

Avoid consuming certain foods and beverages within an hour of taking iron supplements: The tannins in coffee and tea can decrease absorption, says nutritionist Tina Willis, RDN. So can calcium (found in dairy products), folic acid (found in spinach and dark chocolate) and phytates (found in whole grains and legumes).

But vitamin C can help to enhance iron absorption, whether from tomatoes, strawberries or orange juice, so combine iron-rich foods with those rich in vitamin C (think ground-beef chili prepared with tomato sauce).

“I'll tell people, when they are taking the pill or the supplement, to just take it with a very small glass of juice,” Willis says. “It can even be a 4-ounce glass.”

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!

WOMEN'S RETREAT
MARCH 28-29, 2020
NEWPORT BEACH
MARRIOTT

Join us for an overnight educational program! Learn about topics such as PTSD, intimacy issues, and women with bleeding disorders. Separate Teen Programming. HFSC Community Members Only. Ages 13+.

Registration Now Open!
<https://hfscwomensretreat2020.eventbrite.com>

**Hemophilia Foundation
of Southern California**
Invites You To The

SOCIAL EMPOWERMENT FORUM
FEBRUARY 29, 2020
PICKWICK GARDENS, BURBANK

Trusts and Estate Planning for people with chronic conditions
What's Your Story? Learn your 30 second elevator pitch
Insurance Woes? Hear community stories and get help from experts
Sessions in English and Spanish

Register Now:
<https://hfscempowerment2020.eventbrite.com>

BLOODY HOT SALSA CHALLENGE
THE 4TH ANNUAL

Cash Prizes in Spicy, Mild and All-Stars Categories!
NEW for 2020: Industry Category
<https://hfscsalsachallenge2020.eventbrite.com>

Bloody Hot Salsa Challenge

**Hemophilia Foundation
of Southern California**