

HEMOPHILIA ACTION

A PUBLICATION OF THE HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA
VOLUME 15 | ISSUE 2 | SPRING | 2019

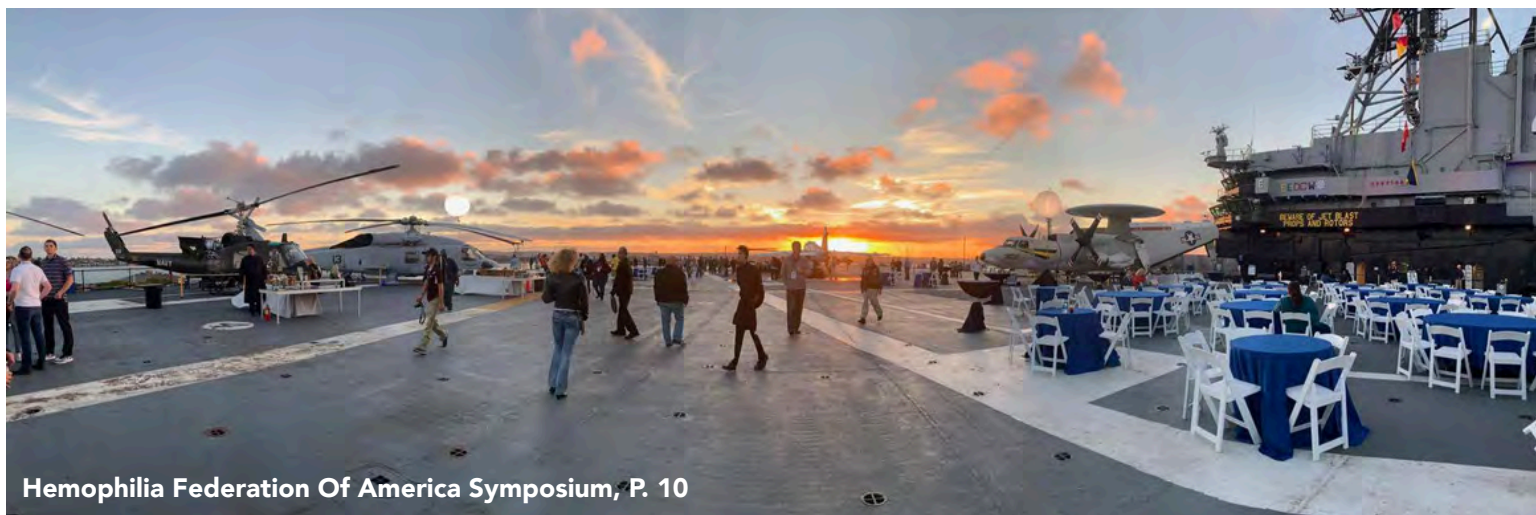


Washington Days, P. 6

Industry Forum, P. 5



EmPOWERment Forum, P. 5



Hemophilia Federation Of America Symposium, P. 10

2019 CALENDAR OF EVENTS

- July 13 **Pain Management and Alternative Therapies Conference**
Pasadena, CA
- July 23-28 **Camp Blood Brothers & Sisters**
The Painted Turtle
Lake Hughes, CA
- August 3 **Back To School Symposium Children's Hospital LA**
Los Angeles, CA
- September 6-8 **Familia de Sangre Conference**
Anaheim, CA
- October 3-5 **NHF Bleeding Disorders Conference**
Anaheim, CA
- November 2 **Unite For Bleeding Disorders Walk**
Griffith Park | Los Angeles, CA
- December 7 **Santa Barbara Holiday Party**
Santa Barbara, CA
- December 14 **Snowflake Festival**
Santa Ana, CA
- December TBD **Riverside Holiday Party**
Riverside, CA

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HEMOPHILIA ACTION

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The Hemophilia Foundation of Southern California



A LETTER FROM THE BOARD PRESIDENT

I am thrilled to serve as the new president of the Board of Directors of HFSC. We have been busy these past few months and we don't plan to slow down anytime soon. Our most recent event was Family Information Day which was a huge success with over 450 people in attendance. We were very excited to be able to provide much-needed information to our families. Over the course of the next few months, we will be busy planning for the Familia de Sangre event for the Spanish speaking community on September 6-8 in Anaheim as well as the Unite For Bleeding Disorders Walk, which will take place on November 2, 2019, in Griffith Park. There are also many smaller events planned over the next few months so make sure to check the website. Please also remember to register kids for Camp Blood Brothers and Sisters at The Painted Turtle so they can experience the life-changing experience of going to camp. My own kids have gone since second grade, with my eldest working in the Leaders in Training program last year. The Painted Turtle is truly a magical place. If you need help with the application please contact the office and ask for help as soon as possible. The application takes time, but it is definitely worth the effort.

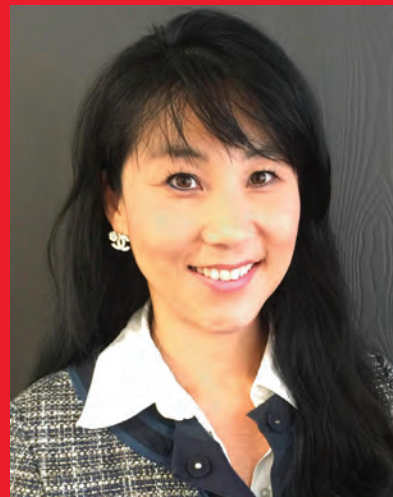
In this time of rapid change and the introduction of new treatments within our community, if there are additional ways we can help, or if you would like us to cover a particular topic at one of our events, please let us know. Our mission is to provide valuable information to the bleeding disorders community and to empower you to make the best-informed decisions possible.

Sandy Knight, HFSC Board President

A LETTER FROM THE EXECUTIVE DIRECTOR

This month marks my fourth year as Executive Director of HFSC and I can't help but marvel at the strides we've made and the incredible vibrancy and resilience of this community. Moreover, after 24 years in the bleeding disorders community, I can't believe the incredible developments in various treatments including non-factor replacement products, gene therapy and gene-editing research for hemophilia. I urge all the community members with hemophilia to gain as much knowledge as possible about all the options that are available. New on our website is a link of available clinical trials being offered in Southern California. If you are interested, know that you don't need to be a patient at the hospital site in order to join the trial. These trials are not only about new medicine but include topics such as quality of life and psychological effects. There are still so many advancements that need to be made, not only with hemophilia but all the other rare genetic blood disorders! I can't wait for the day that we are bleed free! As always, please contact us with any questions or concerns!

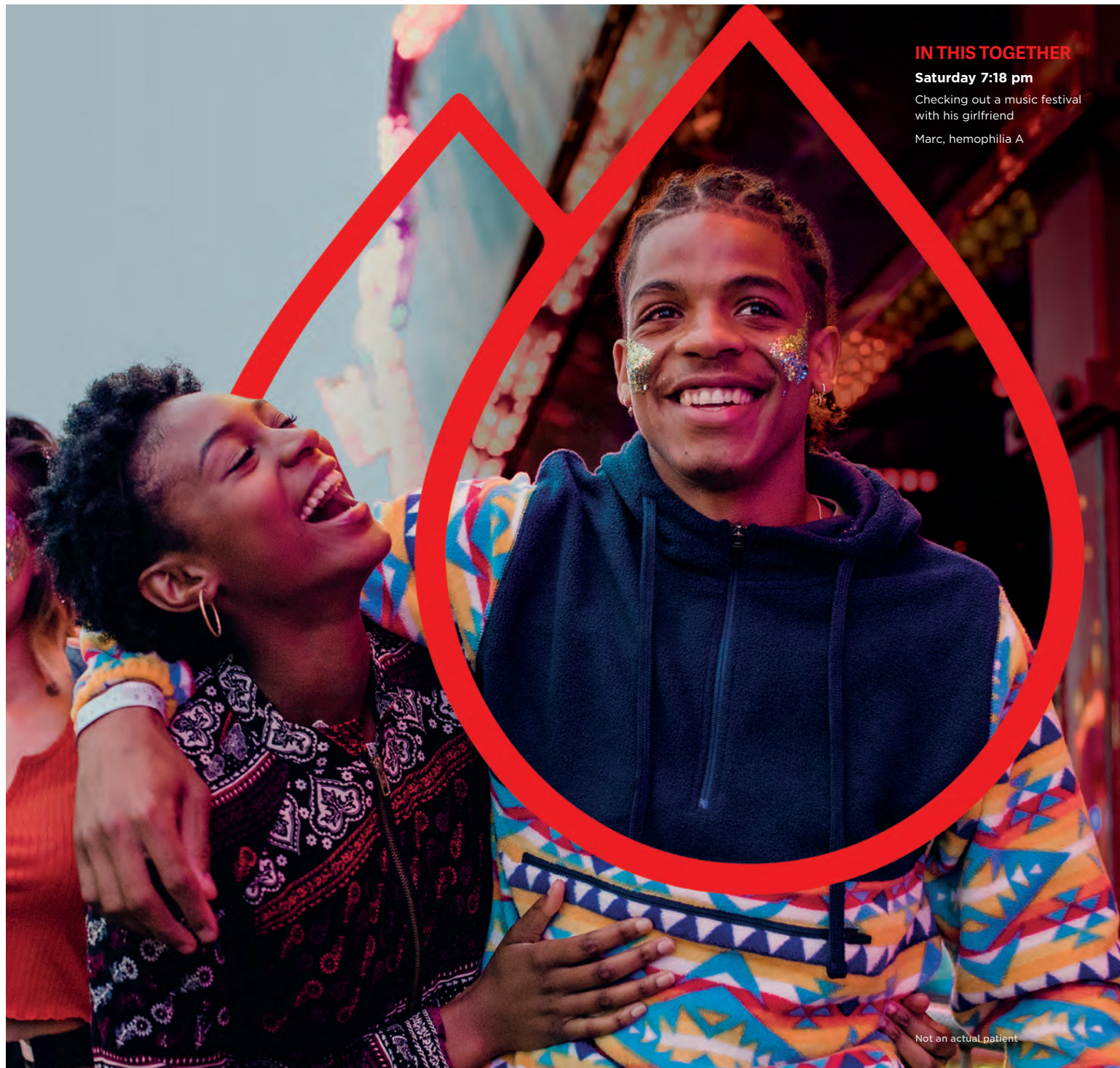
Michelle Kim, HFSC Executive Director



COMMUNITY SPOTLIGHT

Andrew Yu is HFSC's very first high school intern and an HFSC Teen Leader. Andrew interned in the HFSC Office during the summer of 2018, commuting on the Metro each day. During his internship, Andrew assisted in creating a brochure for women with bleeding disorders, created a database of scholarships offered to students in the bleeding disorders community, and conducted legislative visits through the Teen Leadership Summit. Andrew also helped run the HFSC booth at a health fair hosted by Assemblywoman Blanca Rubio, answering questions about the Foundation and educating attendees on bleeding disorders.

Most recently, Andrew has attended events as a volunteer, assisting wherever he is needed. He also attended NHF's Washington Days program in Washington, D.C. in March, where he advocated for legislation to protect the care for those with bleeding disorders. Andrew will be graduating from high school this year and attending college in the fall.



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



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MUJEREZ ENLAZADAS POR SANGRE

Mujerez Enlazadas por Sangre gathered at the Castaway Restaurant in San Bernardino on Wednesday February 13, 2019 to celebrate Valentine's Day! Those in attendance were able to hear from Hector Grisalez, "Knowledge is Power." Hector shared his personal experiences and then opened the floor for the ladies in attendance to do the same. We want to welcome all the new moms who came out to their very first dinner! Thank you, Hector, Denise and CSL Behring for moderating such a great topic and sponsoring such a delicious dinner! The ladies in attendance were rewarded with some Valentine chocolates and cookies!

WOMEN'S RETREAT: MARCH 22-23, 2019: VENTURA, CA

Laughter, Reflection and Sisterhood. HFSC's Women's Retreat held in partnership with Children's Hospital LA (CHLA), at the beautiful beach in Ventura created deep bonds and provided extraordinary education. The event began with succulent crafts donated by HFSC Accountant Susan Hall Hardwick, and ice breakers by Randy DeSantis. Lisa Stoll, Sommelier Extraordinaire of Explore Wines and Kate Ballew, Owner of Strey Cellars, presented "Demystifying the Wine Tasting Experience" with delicious wines donated by Strey Cellars, while the teen girls met separately for a night of games. On Saturday morning, Dr. Julie Jaffray, pediatric hematologist, CHLA, presented on "Women and Bleeding Disorders," followed by breakouts on a variety of topics including "MicroBleeds," by Martina Willis-McCullough, RN, BSN, Nurse Educator, Octapharma, "Mestruacion y pubertad: actividad para madres e hijas," by Vicky Michua, a Steps for Living Moderator, "Living with Loss," by Dr. Cathlyn Buranahirun, Psychologist, CHLA and "I Love a Bleeder: A Session for Partners/Spouses," by Morgan Stowers and Alicia Horta, Community Members. After lunch and a beach visit, women chose from breakouts, "Mindfulness," by Susana Escojido and Amalia Vega, Bilingual Healthcare Educators, Takeda, "Sweet and Sour," by Susan Cole and Esther Ibarra, Community Members, "Advocating for Yourself as a Woman," by Sandra Valdovinos-Heredia, Social Worker, CHLA, and "Manejar el estrés y mejorar el bienestar," by Laura Echandi, Cultural Guia, NHF. Teen girls enjoyed making their own bags with Designer Mesly Guzman and hearing from Sandra! Finally, everyone topped off the retreat by attending a relaxing yoga class with Jessica Oberan Steed from Brothers Healthcare or an interactive self defense class by Joy Woefel of Never Alone Self Defense. Hats off to photographer Linda Clement and our stellar volunteers: Julieta Avalos, Samantha Avalos, Mia Castaneda, Anna Clark, Erika Clement, Aileen O'Brien, Susan Cole, Randy DeSantis, Dawn Espinosa, Noel Figueroa, Sochi Frank, Kelly Lynn Gonzalez, Mesly Guzman, Tatiana Henriquez, Trisha Macias, Judy Mangione, Edith Mejia, Arely Michua, Yatzared Michua, Leticia Nevarez, Mallory Talledo and Silvia Vega!



The Women's Retreat was made possible through a generous grant from:

CK Colburn Keenan Foundation, Inc.

Gold Sponsors:



Thank you to supporters:



Apply Now!

**CAMP BLOOD BROTHERS
AND SISTERS**

July 23-28, 2019

Held at



Call us with questions!

<http://thepaintedturtle.org/campers-families/families/application/>



LA REGISTRACIÓN ESTA ABIERTA

6-8 DE SEPTIEMBRE DE 2019
ANAHEIM MARRIOTT, ANAHEIM, CA



ÚNASE A NOSOTROS

La Fundación de Hemofilia del Centro de California, Asociación de Hemofilia del Condado de San Diego, la Fundación de Hemofilia del Norte de California y la Fundación de Hemofilia del Sur de California están orgullosos de traerles la tercera conferencia estatal: Familia de Sangre, una conferencia de tres días sobre desórdenes sanguíneos presentada en español. Sesiones educativas y oportunidades para establecer conexiones cubrirán importantes temas de cuidado de la salud, educación y servicios de apoyo. El espacio es limitado.

JOIN US

The Central California Hemophilia Foundation, Hemophilia Association of San Diego County, Hemophilia Foundation of Northern California and Hemophilia Foundation of Southern California are proud to bring you the third annual Familia de Sangre, a three-day statewide bleeding disorders conference presented in Spanish.

Educational sessions and networking opportunities will cover health care, education and support services. Space is limited.

**REGÍSTRESE AQUÍ:
REGISTER AT:**

www.familiadesangre.org

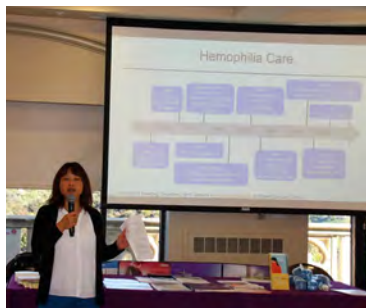
GRACIAS A NUESTRO PATROCINADORES

Titanio: Takeda

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INDUSTRY FORUM | 2019

On a sunny January morning, more than 300 HFSC members attended the 4th Annual Industry Forum held at Mount St. Mary's University in West LA to learn about available products and programs used in the treatment of bleeding disorders. The plenary session was moderated by Dr. Doris Quon of Orthopaedic Hemophilia Treatment Center, and included Industry Snapshot presentations by CSL Behring, Bayer, BioMarin, Novo Nordisk, Octapharma, Grifols, uniQure, Pfizer, Genentech, Bioverativ, and Takeda. After lunch, adults attended their chosen breakouts to learn more about products, and teens attended a presentation by Perry Parker, "Be Active, Find Your Passion, and Be Happy!" sponsored by CSL Behring. Thank you to everyone for joining us!



SOCAL EMPOWERMENT FORUM



On Saturday, February 23, 2019, HFSC hosted its annual So Cal emPOWERment Forum with over 250 people, a day of advocacy training at Pickwick Gardens in Burbank, CA. The morning started with a "History of Hemophilia" activity led by community members Guillermo Campillo and Anna Clark. Next, HFSC was honored to hear from advocate Jeanne White-Ginder who gave a moving presentation about the legacy of her son, Ryan White, and what it meant to be at the center of the HIV/AIDS crisis of the 1980's. Thank you to Rebecca Berenson-Carmona for making a heartfelt introduction. Next, Margaret Vinci of the Cal Tech Office of Earthquake Programs spoke about how to prepare for disasters in the Southern California area, including a demonstration of the new Early Warning System for Earthquakes, ShakeAlertLA, which can be downloaded from the Apple App Store, or from GooglePlay by searching for "ShakeAlertLA." Legislative Advocate Terri Cowger Hill, of Cowger & Associates, shared updates from the capitol and issues on copay accumulator adjustment. After lunch, Health Educators Susana Escojido and Amalia Vega of Platinum Sponsor, Takeda, gave a bilingual presentation on "Resilience" along with an interactive experience for families where they had to build towers out of marshmallows and dry spaghetti.

In the morning, the youth played teambuilding games led by volunteer Ivan Arevalo. Then youth enjoyed a presentation by airbrush artist, Shane Horrell, of Mr. Hoodbrush. They closed the morning and created custom designs that were then airbrushed onto T-Shirts by Shane and his team.

At the end of the day, the group was joined by "The Avengers Initiative" for a photo opportunity while HFSC raffled off various emergency preparedness supplies.

Thank you so much to our inspiring speakers, our amazing volunteers, and to Platinum Sponsor, Takeda.



HFSC Thanks Our Sponsors:

PLATINUM



GOLD



SILVER



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

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WASHINGTON DAYS 2019



On March 23, 2019, HFSC Teen Leaders traveled to Washington D.C. to attend NHF's Washington Days, and represent Southern California and lobbied on Capitol Hill on behalf of the bleeding disorders community. Teens advocated for more than ten meetings with legislators and staff from their respective districts. HFSC is so incredibly proud of the Teen Leaders for all their hard work: Mathew Casas, Mia Castaneda, Glenn Chang, Luke Kim, Carson Knight, Damien Perez and Andrew Yu! Executive Director Michelle Kim, Event Coordinator Casey O'Brien, and HCC Board Representative Tim Stowers attended as well.

A NOTE TO THE BLEEDING DISORDER COMMUNITY

Nadia Ewing, M.D.

Professor Emeritus, City of Hope Medical Center

I am not good at saying goodbye. After 4 months since I retired from City of Hope, I am finally writing down a note addressed to you, my wonderful patients, and the community of persons with bleeding disorders. It has been an honor and a true privilege being entrusted with your care for nearly 4 decades! I could not have accomplished what I set out to do without my fantastic HTC core team, particularly Lisa Pullens (brilliant, knowledgeable, loving and patient nurse coordinator), Lucia Lemus (resourceful, and compassionate social worker), Ahmed Tahun (hardworking, smart, never said no to any request CRA!), and Steve Eggleston (athletic and inspirational physical therapist). I am also grateful to City of Hope for having supported all my programs throughout my 23 years affiliation.

Ever since I was a little girl, I wanted to be a physician. I have no idea how that decision came about when I was 4, since no one in my family was in medicine, but from then on, it was all I ever wanted to do. And so it was that I came from Florence, Italy, to Los Angeles to attend UCLA as an undergraduate, and USC Medical School. As part of my pediatric training, I rotated through the hematology/oncology service, which lead me to develop a passion for that field. I focused on hemoglobinopathies and bleeding disorders having been under the tutelage of 2 inspirational leaders Dr. Darleen Powars and Dr. Carol Kasper. At completion of my fellowship, I joined Orthopaedic Hospital in Los Angeles, and then Huntington Hospital in Pasadena, and finally, in January of 1996, City of Hope, where I founded and directed a federally funded pediatric comprehensive hemophilia treatment center. I am fortunate to have lived through, to have witnessed, and to have been part of the incredible progress in the treatment of blood disorders through my career. When I started, patients with hemophilia were treated with plasma derived lyophilized factor replacement products, manufactured from many thousands of donors. Soon it became clear that these products were contaminated with HIV and hepatitis viruses. Too many lives were lost during these terrible times! However, this deplorable health crisis gave impetus to accelerated research, culminating in the production of much safer recombinant factor concentrates. There was further improvement with the availability of extended half life products, so that infusions could be administered less frequently to control or prevent bleeding. And now, hemophiliacs can be treated with single subcutaneous injections of non-factor products, that rebalance their ability to clot, as infrequently as once per week, once every 2 weeks, or once per month, regardless of whether they have or do not have inhibitors!



Dr. Nadia Ewing (right) with Lisa Pullens (left)

Register Now!

Pain Management and Alternative Therapies Conference

July 13, 2019

Salvation Army Pasadena

960 E. Walnut Street

Pasadena, CA 91106

<https://hfscpainmanagement.eventbrite.com>

Presentations Include:

“Medical Marijuana” with Felicia Carbajal,
California Cannabis Advocates

“Alternative Forms of Pain Management with
the Director of the UCLA Center for East
West Medicine (CEWM)” Dr. Edward Hui

“Patient Pain Panel”

Held in Partnership with
Hemophilia Federation of America

As amazing, as these changes may be, I look forward to more progress, culminating in an actual cure for hemophilia. Several gene therapy trials are in progress, producing amazing and encouraging results! Just think, in a future not too far away, being able to have your own body produce factor after one single vector infusion and you are done!

I may have retired, but have not lost my passion and interest in the field and in the patients, to whom I dedicated such a big part of my life! I plan to share my expertise, knowledge, and experience, and support the younger generations of hematologists, so lucky to enter the field in such exciting times!

I must admit that I am greatly enjoying this new phase of my life, and my newly found freedom to do things for which I had very limited time before, such as exploring and learning about new places in our beautiful world, spending more time with my family, and especially my 5 grandchildren, and taking off somewhere with a friend on the spur of the moment!

HFSC is enormously grateful to the many years of service and dedication provided to the bleeding disorders community in Southern California by Dr. Ewing and Lisa Pullens, RN. Lisa Pullens began working with the HTC Team from Southern California in 1988 with some incredible doctors (Ewing/Tishler/Sanders/Logan & Dietrich with Nurse Coordinator Aggie Gilbert) when patients were admitted to Huntington Hospital. Then in 1990 Lisa began working at the Pasadena HTC with Oncology patients and then Hemophilia and Sick Cell patients relocating with Dr. Ewing to City of Hope to open the new HTC there. She has worked with our community for over 28 years and now with the closing of the HTC at City of Hope, she remains at that hospital in a new role of Nurse Coordinator for Sick Cell Transplant Clinical Trial patients. HFSC thanks you for your service!

A first-person perspective shot of a person's hands holding an open brochure. The person is standing on a wide set of stone steps that lead up a hill. In the background, a large, light-colored stone church with a prominent circular window is visible under a clear blue sky. Other people are seen walking up the steps. The overall scene is bright and sunny, suggesting a pleasant day out.

GO SEEK. GO EXPLORE. GO AHEAD.

Discover your sense of go. Discover HEMLIBRA®.

[HEMLIBRA.com](https://www.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

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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



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Genentech
A Member of the Roche Group



IN MEMORIAM: LOU ALAN MARVIN

Louis Alan Marvin was born July 7, 1937 to Lyle "Joe" Marvin and Cora "Pat" Marvin in Long Beach, CA. At the age of 5 when his dad was a lay pastor at a small church in Seal Beach, CA Lou asked Jesus into his heart. Shortly after that the family pulled up roots and moved to Winona Lake, Indiana where his dad went to seminary. They lived for a few years in Rittman, Ohio and then moved to San Bernardino in 1950, where his dad pastored the Grace Brethren Church. He attended both Sturges and Arrowview Jr. High and graduated from San Bernardino High School in 1955. He attended Valley College for 4 years first getting an AA

degree in Music, then another AA in Electronics. During his last year at Valley he began dating Carole Bond whom he met at church. They were married by Lou's dad in 1961. After college he got a job with North American Aviation, Autonetics Division in Anaheim where he advanced quickly from electronics technician to engineer. Lou also got his ham radio license (WA6CAW) at the end of high school and loved working with anything that involved electronics. He was the go-to guy whenever anyone's TV had problems. Sometimes it only took a whack in the right spot to get it working again. Through the years Lou loved serving the Lord in the churches he attended as pianist, organist, soloist, Deacon, Board member, AWANA leader, Sunday School helper, sprinkler repairman and of course sound system repair. He loved working with children and seeing them learn to love Jesus. In 1976 he moved back to San Bernardino and opened a CB Radio shop named MARCOM Electronics at Waterman and 7th Streets. During that time he attended Southern Illinois University extension at Norton AFB where he earned his Bachelor of Science in Vocational Education. He operated MARCOM for 8 years then went back to working in various aspects of the electronics industry. Lou had a great and very dry sense of humor which endeared him to his friends and family. Recently he enjoyed putting jokes on Facebook every day. He is loved and will be greatly missed by his family and friends, but they are thankful that he is now happy and healthy with Jesus. He is survived by his wife of 57 years, Carole, two sons David (Tami) of Redlands, Donnie (Lori) of Hayden, Idaho and daughter Cyndi Johnson (Barry) of Highland plus 7 grandchildren, Danae, Janise, Karissa, Makayla, Wesley, Emily and Kaylee. He had waiting for him in heaven his parents, his brother Lyle and a niece and nephew. In lieu of flowers, gifts may be given to Immanuel Baptist Church in memory of Lou Marvin.



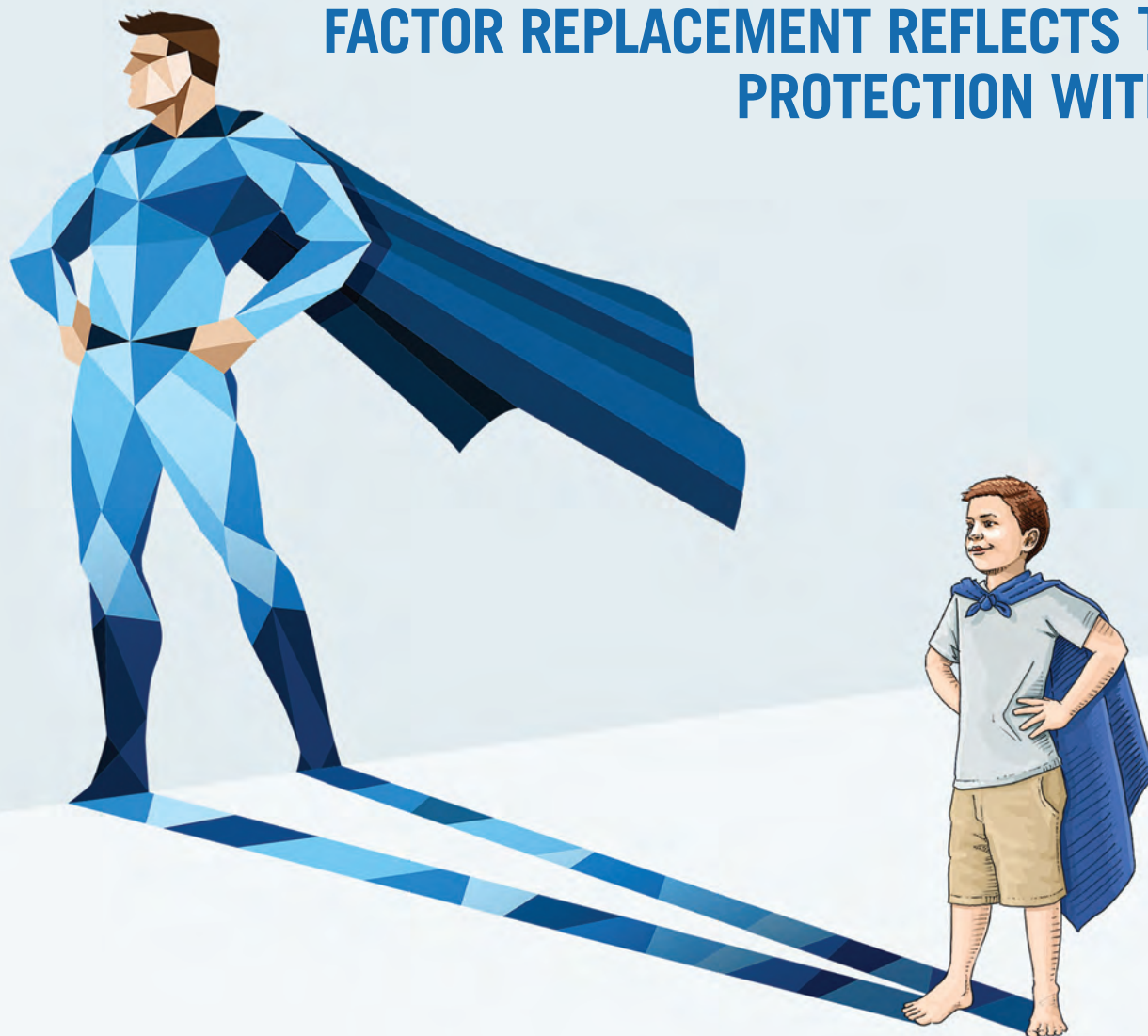
HFA SYMPOSIUM



Many HFSC member enjoyed an incredible conference sponsored by the Hemophilia Federation of America from April 4-7, 2019 in San Diego, CA. We were proud that many of our members were speakers at the event and thankful that the most sacred history room boards were donated to us. HFSC was honored to donate \$1,000 to HFA Smithsonian Project. This project will archive our history with donated artifacts to the Smithsonian Institution! Thank you also to HFA for your incredible generosity in providing many hotel scholarships to us! The Final Night event was extraordinary and truly represented "THE BEST OF US"! Thank you also to all the community members who helped with the HFSC Booth and congratulations to community member, Joslyn Olsen Kelly for receiving the Michael Davon Community Service Award!



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LET'S GO

6 KEY QUESTIONS TO ASK BEFORE TAKING PART IN A CLINICAL TRIAL

Advances in bleeding disorders care rely on research, but is taking part in a study right for you?

Author: Gillian Scott

Novel Technologies, Hemophilia A&B, Von Willebrand Disease

NEW!

www.hemosocal.org now has a new tab "Clinical Trials" which lists all available trials in our area. You do not need to be a patient to enroll! Check it out!

Clinical trials are an important step in the development of new drugs, devices and other treatments for bleeding disorders. Trials help ensure that new treatments are safe and effective before therapies or devices are approved for wider use. In a trial, a group of study subjects is treated with the new product under close supervision by medical experts. Involvement by members of the bleeding disorders community in research is crucial to the success of clinical trials. Typically, a member of your healthcare team, such as your hematologist, will alert you to the possibility of joining a trial. But before you agree to participate, there are some important issues to consider.

Informed consent rules developed by the Food and Drug Administration (FDA) require that potential study participants be told how they'll be treated during the trial, what risks and discomforts they may face, how the trial will work and that their participation is voluntary. Be sure to ask questions about any details you don't understand. As you weigh whether to participate, get answers to the following:

What is the purpose of the trial?

Ask how the treatment or device being tested is different from what's available now and how it might benefit you more than your current treatment.

What are the possible risks?

The FDA emphasizes that although participants may benefit from a clinical trial, they may also see no benefit or be exposed to unknown risks. It's important to understand the possible side effects of the treatment being tested and how those side effects will be handled during the trial.

What will be asked of me during the trial?

Trials often involve tests. Thus it's important to understand what kind of tests and how many you'll need to undergo during the trial. Some trials may require participants to stop taking other medications. Ask if you'll have to stop taking your current factor product? In addition, although some treatments may be done at home or in a doctor's office, some trials require participants to travel to a specific location for treatment. If you need to go to a hemophilia treatment center (HTC), for example, ask how often—and inquire if transportation assistance will be provided.

Who will be in charge of my care?

Ask if you'll be able to keep seeing your own doctor. It's also important to know if the doctors involved in the study will keep your doctor informed about your participation in the trial. Ask if you will be informed about the progress of the trial?

What are the costs of participating in the trial?

Ask if you will have to pay for any parts of the study, who will pay if you are injured during the trial and if insurance may cover any of the costs.

CenterWatch, a resource center for information on clinical trials, offers a sample list of questions patients should ask before agreeing to participate in a study. These include questions about the trial itself, the care patients will receive, the clinical trial procedures (such as withdrawing from the trial) and potential costs to participate.

If you are interested in taking part in a clinical trial, speak with your healthcare team at your hemophilia treatment center. You can also search for trials on ClinicalTrials.gov, a US National Library of Medicine database of publicly and privately funded clinical studies around the world.





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¡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!



Save the Date!

5th Annual Back to School Educational Symposium

August 3, 2019
CHLA



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Crystal Springs Picnic Area | 8:30AM - 1:00PM

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