

# HEMOPHILIA ACTION

A PUBLICATION OF THE HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA

VOLUME 18 | ISSUE 2 | SPRING | 2022

## 2022 INDUSTRY FORUM

HFSC was thrilled to host Industry Forum, the first in-person event of the year on Saturday, March 5 at Pasadena City College. More than 200 attendees enjoyed sponsor booth time on the campus quad, and breakfast provided by InfuCare Rx. Members then proceeded to the classrooms to attend breakout sessions from sponsors on a variety of topics including gene therapy and new treatment options. Teens had a fun time participating in team building activities on the quad with Jerry Garcia, and children played and made crafts with The Painted Turtle. Thank you to all of our volunteers for your help with this event and thank you to our members for joining us in person!

*Thank you to our Platinum Sponsors!*



## 2022 WOMEN'S RETREAT

After two years of hosting the Women's Retreat virtually, members were overjoyed to attend the 2022 Women's Retreat at the Marriott Irvine Spectrum on March 19 - 20. Read the full article on page 6!



# 2022 CALENDAR

Community Dinner  
Luminarias | Monterey Park, CA  
July 12

emPOWERment Webinar Series  
(Virtual)  
July 13

Camp Blood Brothers and Sisters  
The Painted Turtle | Lake Hughes, CA  
July 19 - 23

BRO Golf Outing  
Top Golf | Ontario, CA  
July 31

8th Annual Back to School  
Education Symposium  
Pasadena City College | Pasadena, CA  
August 6

emPOWERment Webinar Series  
(Virtual)  
August 17

NHF 75th Bleeding Disorders Conference  
Houston, TX  
August 25 - 27

6th Annual Familia de Sangre Conference  
Anaheim Marriott | Anaheim, CA  
September 23 - 25

Unite for Bleeding Disorders Walk  
LA Coliseum | Los Angeles, CA  
October 29

## HEMOPHILIACTION

is published quarterly by

The Hemophilia Foundation of Southern California

# THANK YOU DONORS

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Harry and Juanita Boessler, in honor of Tyler, Abby and Michael  
Jane Brady, in honor of Amelie Iavicoli  
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Joan Parker, in honor of Perry & Corey Parker  
Sudha Yeluri, in honor of Vijay Prathigudupu

## In Memory

Joanne and James Hitchens, in memory of Susan J. Stone  
William and Judy Metscher, in memory of Richard Katz  
John Truxaw, in memory of Chris, Joe, and Tom Hays

## Grants and Corporate Gifts

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## A LETTER FROM THE BOARD PRESIDENT

As many of you know, after eight years of extraordinary service to the Southern California bleeding disorders community, Michelle Kim will be resigning as HFSC's Executive Director.

Since Michelle stepped into this role and under her leadership, HFSC has developed innovative, educational, and support programs for the community, ensured financial sustainability for the Foundation, and reaffirmed our commitment to our mission.

The Board has engaged Sterling Search Inc. to assist us in selecting a candidate who will continue to successfully deliver on the organization's mission. Our mission won't change with the upcoming change in leadership, and we are indebted to Michelle for greatly improving our ability to achieve that mission by bringing about a

significant evolution for the Foundation's leadership as well as its work. Whenever the new ED is chosen, Michelle has graciously offered to assist him or her in the transition process and to be available for consultation for however long it takes to ensure a successful and smooth transition.

Under her guidance, HFSC has become a strategic foundation able to work effectively in a complex and ever-changing landscape, and we are grateful to have benefited from her transformative leadership. During her tenure, she has worked tirelessly advocating on behalf of the bleeding disorders community, and we are extremely fortunate to have worked alongside a leader with her passion, intellect, creativity, and commitment.

Thank you, Michelle, on behalf of all of us, for your inspiration, determination, and guidance, in service of those in the rare bleeding disorders community. We look forward to continuing to see Michelle as a community member at HFSC events in the future! - Rick Kelly, MBA

## A LETTER FROM THE EXECUTIVE DIRECTOR

After 8 years of service to the Hemophilia Foundation of Southern California, as some of you know, I will be resigning as Executive Director. Balancing my work with the responsibilities of raising a child with multiple serious and life limiting conditions has been challenging, but I have served with exuberance, dedication and passion developed from this personal experience of advocating for and overcoming many challenges faced by people with rare disease.

My daughter's current condition requires that I devote more time to her care. I cannot give this job the same level of dedication and therefore it is with great sadness that I submit my resignation as ED. It has been an extraordinary honor to serve this vibrant and resilient community. But, we also know that the Foundation is not about one person, and it is all of you - community members, volunteers, staff, medical providers, pharmaceutical companies, nonprofit partners, medical advisors and amazing board members - that make such a vibrant community. I believe that whoever steps into this new role will be set up for success due to the support of a skilled Board of Directors, passionate and talented staff, an established infrastructure and innovative programs in place.

I will assist in the transition process during this summer and will be available for consultation for however long it takes to ensure a successful and smooth transition. It goes without saying that I will always proudly and joyfully remain part of the community. My deepest love and thanks to all who supported me during this most exciting career journey of a lifetime. - Michelle Kim, Esq.



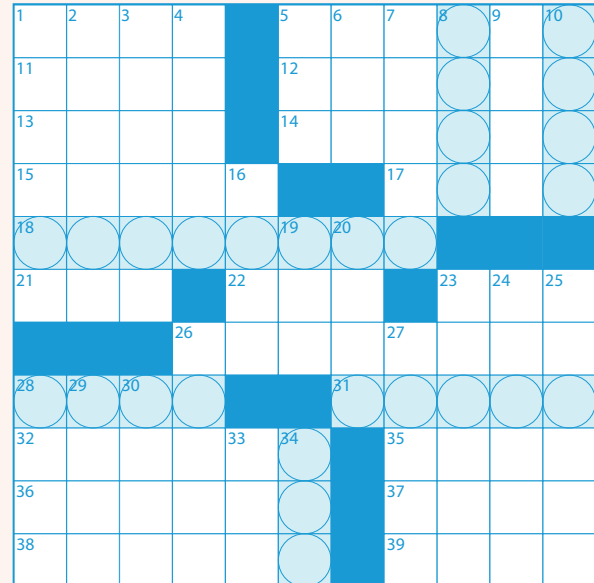


**CAN YOU SOLVE**

# FOR A DIFFERENT HEMOPHILIA A

**TREATMENT?**

Test your HEMLIBRA knowledge



## ACROSS

1. Wine barrel
5. Deep fissures
11. Mideast gulf port
12. District
13. Ripped
14. Familiar with
15. Mean
17. Roost
18. The #1 prescribed prophylaxis for people with hemophilia A without factor VIII inhibitors\*

\*According to IQVIA claims data from various insurance plan types from April 2020 - May 2021 and accounts for usage in prophylaxis settings in the US.

21. Calendar divs.
22. Regret
23. Banquet hosts (abbr.)
26. International travel necessity
28. Check out the \_\_\_\_\_ treated bleeds data with HEMLIBRA
31. Number of dosing options HEMLIBRA offers

\* Number of people with hemophilia A treated as of October 2021.

32. Small hole in lace cloth
35. Central Plains tribe
36. Melodic
37. Towering
38. Reduce
39. Spanish cheers

## DOWN

1. Memorable, as an earworm
2. Devotee
3. Medical fluids
4. Prepare to propose, perhaps
5. PC's "brain"
6. Owns
7. Concert venue
8. See Medication Guide or talk to your doctor about potential \_\_\_\_\_ effects
9. Winter hrs. in Denver and El Paso
10. HEMLIBRA is the only prophylactic treatment offered this way under the skin

16. Pre-Euro currency in Italy
19. Subway alternative
20. Relax
23. Human
24. New Orleans cuisine
25. Mentally prepares
26. Collared shirts
27. Instagram post
28. Ardent enthusiasm
29. Brontë heroine Jane
30. Old Portuguese coins
33. Opposite of WNW
34. More than \_\_\_\_\_ thousand patients have been treated with HEMLIBRA worldwide\*

## SOLUTIONS

Across: 1. cask, 5. chasms, 11. Aden, 12. parish, 13. tore, 14. used to, 15. cruel, 17. nest, 18. HEMLIBRA, 21. yrs, 22. rue, 23. MCs, 26. passport, 28. zero, 31. three, 32. eyelid, 35. Ome, 36. arioso, 37. tall, 38. lessen, 39. oles  
Down: 1. catchy, 2. adorn, 3. serums, 4. kneel, 5. CPU, 6. nas, 7. arena, 8. side, 9. MIST, 10. shot, 16. lire, 19. bus, 20. rest, 23. mortal, 24. Creole, 25. steel, 26. polos, 27. photo, 28. zeal, 29. Eyre, 30. Reis, 33. ESE, 34. ten

Discover more at [HEMLIBRA.com/answers](https://HEMLIBRA.com/answers)

## INDICATION & IMPORTANT SAFETY INFORMATION

### 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. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.**

### These serious side effects include:

- **Thrombotic microangiopathy (TMA)**, a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- **Blood clots (thrombotic events)**, which may form in blood vessels in your arm, leg, lung, or head

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





**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.**

**Your body may make antibodies against HEMLIBRA, which may stop HEMLIBRA from working properly. Contact your healthcare provider immediately if you notice that HEMLIBRA has stopped working for you (eg, increase in bleeds).**

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](http://www.HEMLIBRA.com) or call 1-866-HEMLIBRA.  
This Medication Guide has been approved by the U.S. Food and Drug Administration  
Revised: 12/2021



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# 2022 WOMEN'S RETREAT

*(continued from cover)*

The event began with journal making to create a personalized gift for themselves. To begin the retreat with a mental health focus, Cristol Barrett O'Loughlin, Founder and CEO of Angel Aid Cares, spoke over lunch on "Chronic Stress: The Science of Soul Care." Following this presentation, attendees chose from various breakout sessions: "Reproductive Health," presented in English and Spanish by Maria Tovar-Herrera; "Mental Health Rap Session," Moderated in English and Spanish by Erika Bocanegra, MSW; "Updated vWD Guidelines: What You Need to Know," Dr. Doris Quon; "Treatments for Mild Hemophilia," Dr. Nina Hwang; and "Tai Chi" with Rick Starks sponsored by CSL Behring. Teens gathered to make succulent plants and have a discussion with Dr. Terez Yonan of CHOC.

The evening kicked off with a wine and cheese reception on the lawn before the dinner presentation, "Gratitude Nation," by Albert Maffei, sponsored by Sanofi. Sunday morning began with breakfast and "Women Have Bleeding Disorders Too," a presentation from Dr. Claudio Sandoval, sponsored by Octapharma. The women then said their goodbyes and departed the hotel. Thank you to all our amazing volunteers!

*Thank you to our Sponsors!*

**Gold Sponsor**



**Silver Sponsors**

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Biotherapies for Life™





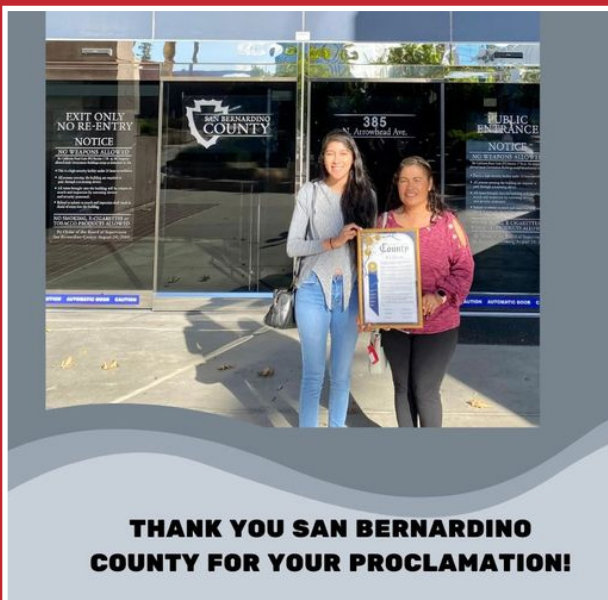
# MARCH IS BLEEDING DISORDERS AWARENESS MONTH



Thank you to all who donated,  
in honor of **Bleeding Disorders  
Awareness Month!**

Because of your generous support,  
we raised nearly **\$8,000** to help  
us provide **scholarships** for our  
community members!

Amazon Smile • Anonymous (3) • Marilyn Borowsky • Matt and Hazel Borowsky • Rachel Borowsky  
Carolina Bowers • Andrew Casas • Mathew Casas • Carlos Chavez • Cynthia Chavez • Soledad Chavez  
Katrina Clayton • The Desai Family • Diane Dotson • Edison International • The Guillow Family • Wayne Guzman  
Mollie Heiser • The Iavicoli Family • The Kelly Family • The Kim Family • Sandra and Shawn Knight • Kroger  
Steve Lowe • Microsoft • Tracy Napoleon • Robert Numerof • Aileen O'Brien • Casey O'Brien  
Don and Anne Polkingharn • Camden Postiff • Jax Postiff • Tim and Summer Postiff • Mike Queen • Doris Quon  
Nicholas Reminder • Jack Renauer • Jennifer Rono • Jennifer Shields • Kathie Simpson • Marisa Sutherland  
The Swatts Family • United Way • David Warner • Michele and Doug Warner • Jeffrey and Mary Lou Wright



**THANK YOU SAN BERNARDINO  
COUNTY FOR YOUR PROCLAMATION!**

## SAN BERNARDINO BOARD OF SUPERVISORS

HFSC thanks the San Bernardino County Board of Supervisors for recognizing and issuing a proclamation on behalf of our community and promoting awareness for those living with rare bleeding disorders! This is the first time HFSC has received this recognition in San Bernardino County, and we are grateful for your support and service. Thank you also to Maria and Cristina Alvarado who accepted this proclamation on behalf of HFSC!





## BAKERSFIELD COMMUNITY DINNER

On February 22, 2022, we were excited to see the Bakersfield community come together for an amazing educational presentation presented by Silvia Vega from Bayer on post-pandemic dialogue.

Thank you, Rose Cardenas, our Community Liaison in Bakersfield, for hosting!

Thank you to Bayer for your support!

## BLEEDERS REACHING OUT (BRO) GROUP DINNER



BRO gathered together on March 30, 2022 at the famous Dal Rae Steakhouse in the City of Pico Rivera to learn about Gene Therapy! Thank you, Billy Duckworth, for an excellent presentation and BioMarin for your support! Also, thank you Rigo Manzo for helping lead the group!

# COMMUNITY SPOTLIGHT: HFSC HISTORY - THE HAYS FAMILY



*Thank you to Terry Hays-Horner for sharing this rich history of HFSC!*

In the 1950s and 60s, the Hays family were part of the group of parents in the San Fernando Valley who founded the Hemophilia Foundation of Southern California to support kids with Hemophilia. Of the three boys in the family, Joe and Chris both had hemophilia. The whole family pitched in with fundraisers, especially with Bingo. In the early days, treatment for patients included blood plasma transfusions; bottles of Plasma were often stored in the family's refrigerator.

Verne and Chris Hays both served on the Board of Directors, and Terry, Chris, and Verne all volunteered at Camp Blood Brothers that was held each summer in the Angeles Forest. Camp was a place where kids with hemophilia learned the new skill of self-infusing their

medication. They also learned crafts from Terry, photography from Chris, and fishing from Verne.

Sadly, as with so many in the bleeding disorders community, Chris passed away at age 42 after he developed HIV and Hepatitis C from contaminated blood products; he had undergone a liver transplant that was rejected.




## HEMO Hallo-Walk

**HFSC'S UNITE FOR BLEEDING DISORDERS WALK**  
October 29, 2022 • 9 am-1 pm  
LA MEMORIAL COLISEUM

**Come Dressed In Your Most Spooktacular Costume!**

Register today for our largest fundraiser of the year, in support of advocacy and access to care, educational and support programs, research, and Camp Blood Brothers & Sisters!

[UNITEFORBLEEDINGDISORDERS.ORG/EVENT/SOCAL](https://uniteforbleedingdisorders.org/event/socal)





## WE'RE IN THIS TOGETHER.

**Friday 6:26 pm**

Sharing stories by the  
campfire with friends

Isaac, living with  
hemophilia B

Not an actual patient

### Let's make today brilliant.

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world is stronger than ever.

 [bleedingdisorders.com](https://bleedingdisorders.com) | 

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# emPOWERment WEBINAR SERIES

*Wednesday, February 9th*

HFSC hosted the first emPOWERment Webinar on February 9, "What's New in Legislative Advocacy?"

Attendees first heard updates on the national level from Nathan Schaefer, MSW, Vice President of Public Policy at the National Hemophilia Foundation; Lynne Kinst, Executive Director of the Hemophilia Council of California presented updates from the state.

The webinar concluded with attendees hearing from our sponsors.



*Wednesday, March 23rd*

Over 60 community members joined HFSC virtually on March 23 for our second webinar in our emPOWERment Webinar Series, "Surgical Interventions for Pain Management."

Speaker James Luck, Jr., MD, Director of Surgical Services and Rehabilitation, Orthopaedic Hemophilia Treatment Center, shared the different ways in which surgery can help manage pain, including hip, elbow, and ankle replacements.

Dr. Luck is a board-certified orthopedic surgeon specializing in hemophilia disorders, bone and soft tissue tumors and joint reconstruction and has been actively involved with the Hemophilia Treatment Center since 1968. He has performed more reconstructive surgeries on hemophilia patients than almost any other surgeon in the world.

Thank you, Dr. Luck, for this informative and valuable presentation!

*Thank you to our Sponsors!*

*Platinum Sponsors*



*Gold Sponsors*



*Silver Sponsors*



# VOLUNTEER SPOTLIGHT: CHRISTINA AND ETHAN OLIVARRIA

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Christina and her son, Ethan (14), from Pomona, have been involved with HFSC since Ethan's first time at Camp Blood Brothers and Sisters at The Painted Turtle. They started volunteering at events like the Unite Walk prior to the pandemic, helped out during virtual events the last few years, and have been volunteers twice this year in-person at Industry Forum and Family Information Day. They are usually joined at events with the rest of the family including Jose, Evalynn, and Elias, as well as Christina's dad, Wayne (who also happens to be on the HFSC Board). As a family, the Olivarrías enjoy being outside riding bikes and hiking in national parks to connect with nature. They also have two dogs, Rupert and Puppy.

Ethan was diagnosed with severe hemophilia A at Children's Hospital of Orange County one week after he was born. Over the years, they have participated in many HFSC events, their favorites being the Family Retreat and the Shaka Surf Fest.

When asked about what HFSC does for them as community members, Christina said, "For us, I believe it is the experience of being around people who understand you, who get what you are going through like no one else does. HFSC is a special chapter, as it unites us together not just in educational settings but also in shared experiences with our families, whether it be tai chi, surfing, or singing 'Ice Cream and Cake.' Self-advocacy and empowerment are common themes in the sessions that are foundational for managing a lifelong genetic disorder. Focusing on the whole person, not just the diagnosis, has been something we have shared with Ethan since he was very young. We appreciate that being reaffirmed in the HFSC community."

We are so thankful for all the time and help that Christina and Ethan provide for us and look forward to their support of HFSC in the future!





# YOUR HEMOPHILIA HOME IS HERE.

## The most comprehensive hemophilia program for children and adults in Southern California.

- Coordinated team of specialists, including physicians, orthopaedic surgeons, pharmacists, physical therapists, a nurse practitioner and a social worker under one roof
- Nearly 60 years of experience, with more orthopaedic procedures done on patients with hemophilia than any other center in the US, according to the National Hemophilia Foundation
- Telehealth and in-person appointments
- In-house pharmacy that delivers directly to your door
- 24/7 on-call patient care provider and pharmacist
- Medication management and education
- On-site assistance with navigating insurance barriers and resolving billing issues
- As a 340B pharmacy, all proceeds are put back into the HTC to sustain and create services for our patients and the hemophilia community

Conveniently located directly off the 110 freeway at 403 W Adams Blvd in downtown Los Angeles.

HTC: 213-742-1402 Pharmacy: 213-742-1128



Orthopaedic  
Institute for Children  
Hemophilia Treatment Center

IN ALLIANCE WITH **UCLA** Health

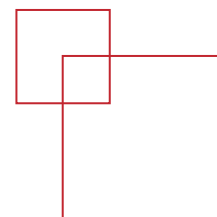
[ortho-institute.org/hemophilia](http://ortho-institute.org/hemophilia)



# SPRING NEWSLETTER

## MEDICAL ARTICLE

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### **Bone Health in VWD and Hemophilia Carriers the Focus of Retrospective Study**

The issue of poor bone health represents a significant public health concern in the U.S. population, including for individuals with hemophilia who are at increased risk for low bone mineral density (BMD) and bone fractures. While low BMD in hemophilia has been the focus of previous studies – linked to recurrent joint bleeding, decreased weight bearing, and immobility – less is understood about this complication in other groups. Hemophilia carriers (HCs) and persons with von Willebrand disease (PWvWD) are two such groups.

A team of investigators therefore conducted a population level, retrospective study to learn more about the prevalence of osteoporosis, osteoarthritis, and bone fractures in both HCs and PWvWD. The study, led by hematologist Divyaswathi Citla-Sridha, MD at the University of Arkansas for Medical Sciences, was published on April 13, 2022, in the journal *Haemophilia*.

Citla-Sridha and colleagues reviewed de-identified electronic health record data culled from 26 major integrated healthcare systems, encompassing 360 hospitals. 940 HCs and another 19,580 PWvWD were identified. The prevalence of osteoporosis, osteoarthritis, and fractures were reported to be “significantly higher” among both the HC and PWvWD data groups.

Within the HC group, investigators observed higher rates of risk factors often associated with low BMD, including vitamin D deficiency, obesity, hypothyroidism, smoking, corticosteroid use, malignancy, and the use of nonsteroidal anti-inflammatory drugs (NSAIDs). The prevalence of risk factors was also higher in the PWvWD group. In light of these findings, the authors signal the need to screen these patients for risk factors for poor bone health, while also providing education to prevent complications.

“This study highlights the need for Haemophilia Treatment Centres to focus on the bone health in these patients and pay closer attention to other risk factors during their routine comprehensive visits,” concluded the authors. “Further prospective, multi centre studies are necessary to validate these findings.”

*Reprinted with permission: “Bone Health in VWD and Hemophilia Carriers the Focus of Retrospective Study,” National Hemophilia Foundation, May 9, 2022.  
<https://www.hemophilia.org/news/bone-health-in-vwd-and-hemophilia-carriers-the-focus-of-retrospective-study>.  
Accessed 23 May 2022.*

6° ANUAL



23-25 DE SEPTIEMBRE DE 2022  
ANAHEIM MARRIOTT

## REGÍSTRESE AHORA

¡Para la conferencia más grande de desórdenes  
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[HTTP://WWW.FAMILIADESANGRE.ORG/REGISTER/](http://www.familiadesangre.org/register/)

## THE NATIONAL ORGANIZATION FOR RARE DISORDERS (NORD)



The National Organization for Rare Disorders (NORD) by its Board of Directors has approved Hemophilia Foundation of Southern California to become a Platinum NORD member organization.

NORD, a 501(c)(3) organization, is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 300 patient organization members, is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.



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

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





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