

HEMOPHILIA ACTION



Hemophilia Foundation
of Southern California
FOR ALL BLEEDING DISORDERS

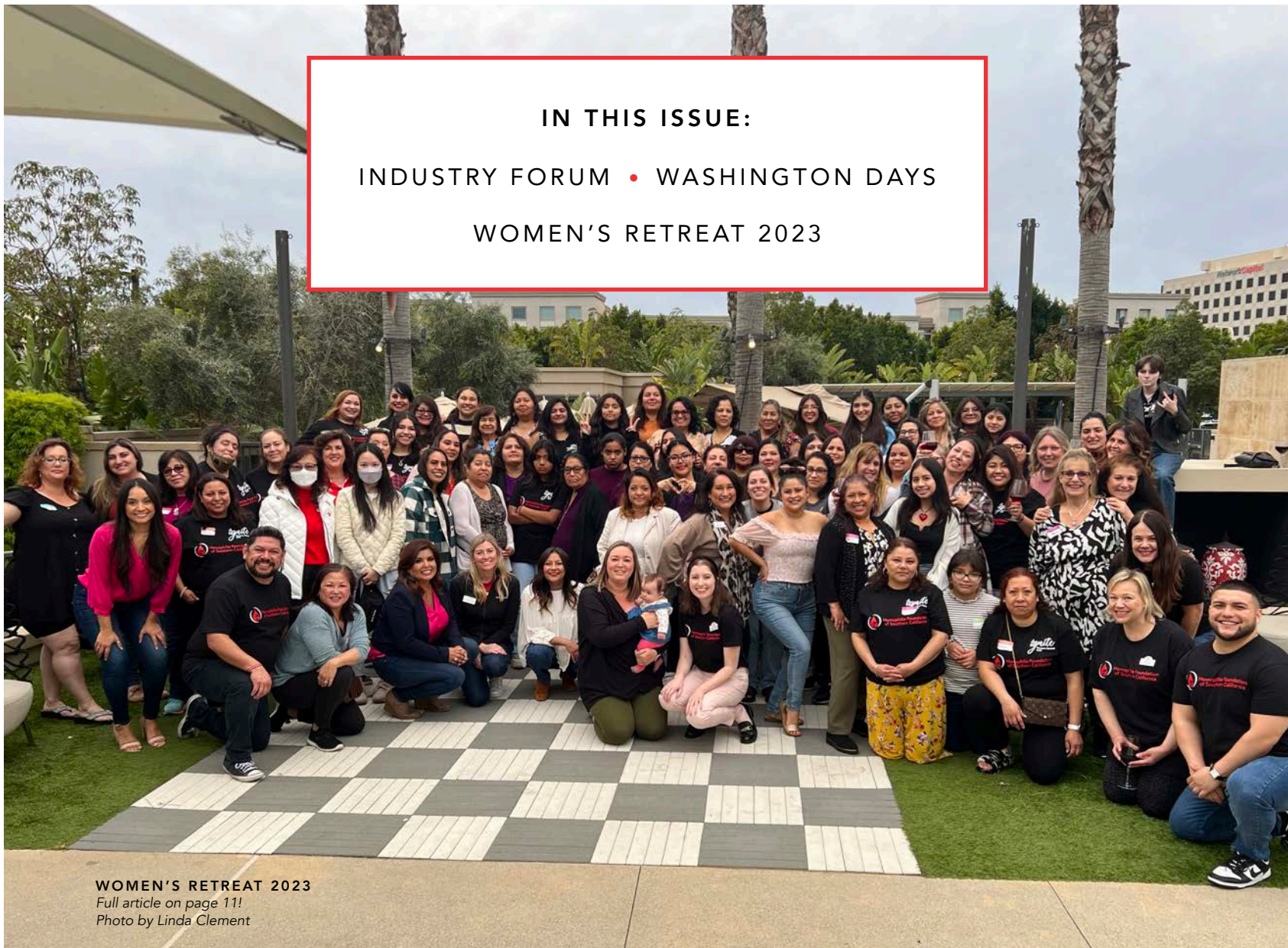


VOLUME 20 • ISSUE 2 • SPRING • 2023

IN THIS ISSUE:

INDUSTRY FORUM • WASHINGTON DAYS

WOMEN'S RETREAT 2023



WOMEN'S RETREAT 2023

Full article on page 11!
Photo by Linda Clement

HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA

959 EAST WALNUT STREET • SUITE 114 • PASADENA, CA 91106
P 626.765.6656 • F 626.765.6657 • WWW.HEMOSOCAL.ORG • INFO@HEMOSOCAL.ORG

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HEMOPHILIAACTION is published quarterly by
THE HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA

GENERAL

Anonymous (3) • Grant and Catherine Wadman

IN HONOR

Harry and Juanita Boessler, in honor of Tyler, Abby and Michael
Jane Brady, in honor of Amelie Iavicoli
Brenda Gonzalez, in honor of Matteo Salcida
Gloria Hernandez, in honor of Matteo Salcida

IN MEMORY

Sharon Hylton Filsinger, in memory of Mike Hylton
Rocky and Wynne Girard, in memory of Melissa A. Hodges
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2023 CALENDAR

WOMEN'S COMMUNITY DINNER

May 10 • Maggiano's, Costa Mesa, CA

EMPOWERMENT WEBINAR SERIES

May 17 • Virtual Event

HFSC COMMUNITY DINNER

May 23 • Café Roma, San Luis Obispo, CA

FAMILY RETREAT WEEKEND

June 2 - 4 • Pali Mountain Retreat, Running Springs, CA

SHAKA SURF FEST & BEACH DAY

June 24 • Santa Monica Beach, Santa Monica, CA

EMPOWERMENT WEBINAR SERIES

July 12 • Virtual Event

CAMP BLOOD BROTHERS AND SISTERS

July 16 - 21 • The Painted Turtle, Lake Hughes, CA

HFSC COMMUNITY DINNER

July 27 • Location TBD, Riverside, CA

7TH ANNUAL FAMILIA DE SANGRE

September 8 - 10 • Anaheim Marriott, Anaheim, CA

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A LETTER FROM THE BOARD PRESIDENT

HFSC has been busy these past few months hosting several dinners and webinars in addition to larger events including Industry Forum and the Women's Retreat. During Bleeding Disorders Awareness Month in March, HFSC staff and community members traveled to both Washington DC and Sacramento to advocate for those affected by bleeding disorders. Thank you to all who met with federal and state lawmakers and for doing such a wonderful job of advocating for our community!

I am looking forward to seeing everyone at HFSC's next event, Family Information Day, on May 6 at the Sheraton Cerritos, where we are 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 Familia de Sangre, a three-day educational conference

to empower, advocate and educate Spanish-speaking community members. The event will take place September 8-10 at the Anaheim Marriott.

Please also remember to register your children for Camp Blood Brothers and Sisters at The Painted Turtle July 16-21, so they can participate in the life-changing experience of going to a camp where they meet others like them while also learning about the life-saving technique of self-infusion and receiving education about their bleeding disorders. My son has attended for 3 years; The Painted Turtle is truly a magical place. If you need help with the application, please contact Omar at omar@hemosocal.org and ask for help as soon as possible. The application takes time, but is definitely worth the effort.

Not only do we have exciting events on the horizon, but we are working hard to raise funds that will provide many opportunities for our bleeding disorder community members. Speaking of raising funds, I ask that each of you sign up for our superhero-themed walk on November 4. Get a team together, ask your family, friends, and neighbors to join in and contribute. This event is an amazing opportunity to raise money for our community, in support of advocacy and access to care, educational support programs, emergency financial assistance, Camp Blood Brothers & Sisters, and research. Registration is open at www.uniteforbleedingdisorders.org/event/socal.

Thank you all for your continued support, and I look forward to seeing you soon! In the meantime, please feel free to reach out to me with any questions or if I can help in any way. To register for any events, please visit www.hemosocal.org. - Rick Kelly, MBA

A LETTER FROM THE EXECUTIVE DIRECTOR

Springtime, a time that is usually connected with a new beginning or transformation. A time where we do some cleaning and even hit the reset button. Think of what the Hemophilia Foundation of Southern California means to you. How can you be more involved? What can we do to get you more involved? What can we do to continue to grow together? This is the question I would like each and every one of our community members to think about and to answer. Let us know how we can continue to provide high quality programming to meet your needs. Spring is a time where we work to continue our growth!

We are a united community, and sometimes we need to pull together, not only during the good times, but when times are tough. I ask that during this time we take a minute to remember our loved community member who left us too soon, Leticia Nevarez; may the great memories she shared with the community get you through this tough time.

At the next event you attend, I ask you to reach out and meet someone new, make a new connection, make a new friend. We know each other because someone extended their hand and said hello to us. Let's make sure that we continue the warm welcome to new community members, just like I was welcomed with open arms not too long ago. May we continue to support one another and may we continue to grow as one. - Rigo Garcia, MPH



INDUSTRY FORUM - PIPELINE PRODUCTS

JANUARY

01.18.23

On Wednesday, January 18, HFSC hosted a Pipeline Products Webinar as a precursor to the in-person Industry Forum event. 75 families logged on to hear presentations from the Medical Directors of Southern California's HTC's: Dr. Doris Quon of Orthopaedic Treatment Center, Dr. Amit Soni of Center for Inherited Blood Disorders, and Dr. Guy Young of Children's Hospital Los Angeles. Attendees also heard a quick word from our sponsors about what they would be presenting at the in-person event.

Thank you to our Medical Directors for speaking and thank you to our sponsors for their support.



INDUSTRY FORUM - PASADENA CITY COLLEGE

JANUARY

01.21.23

HFSC was pleased to host Industry Forum on Saturday, January 21 at Pasadena City College. More than 200 attendees enjoyed sponsor booth time outside on the campus quad, with a light breakfast provided by InfuCare Rx. Community members continued to the classrooms to attend breakout sessions from sponsors on a variety of topics including gene therapy and new treatment options. Children were excited to attend The Painted Turtle Outpost, where they made crafts and played games with Painted Turtle Staff.

Thank you to all our volunteers for their help with this event and thank you to our community members for joining us!

THANK YOU TO OUR PLATINUM SPONSOR, BAYER!





Hemophilia Foundation
of Southern California

**APPLY
NOW!**

CAMP BLOOD BROTHERS AND SISTERS

JULY 16 - 21

**AT THE PAINTED
TURTLE**



APPLICATIONS NOW OPEN!

**Spots limited, apply today!
Must be fully vaccinated to attend.**

Apply:

<https://www.thepaintedturtle.org/apply>

Applications must be completed by July 6

emPOWERment WEBINAR SERIES

FEBRUARY

02.08.23

HFSC hosted the first emPOWERment Webinar of 2023 on February 8, "What's New in Legislative Advocacy?" Attendees first heard updates on the national level from Josie Gamez, Government Relations Manager, at the National Hemophilia Foundation. Lynne Kinst, Executive Director of the Hemophilia Council of California, then presented local updates from the state. The webinar concluded with attendees hearing from our sponsors.

THANK YOU TO OUR emPOWERment SPONSORS!

PLATINUM

sanofi

GOLD

BIOMARIN

CSL Behring
Biotherapies for Life™

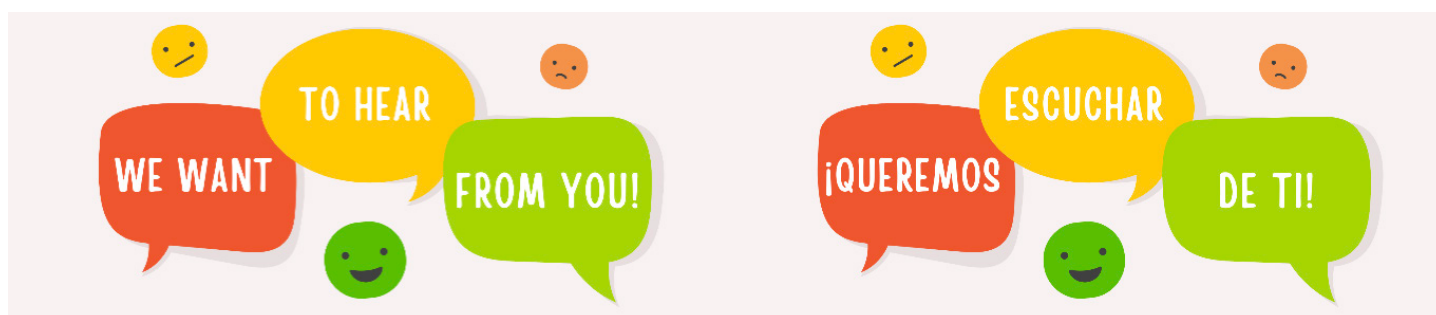
Takeda

octapharma

SILVER

Pfizer

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MUJERES & BRO WEBINAR

We recently held two webinar events where we sought input from our community groups, Mujeres Enlazadas por Sangre and Bleeders Reaching Out (BRO), on how to enhance our future programs. The "Mujeres Enlazadas por Sangre: ¡Queremos escuchar de ti!" webinar was held on February 15, 2023, and the "BRO: We Want to Hear From You!" webinar was held on March 1, 2023. Community members were encouraged to share their feedback on previous events they enjoyed, areas where we could improve, and ideas for new programming to introduce. We received valuable insights from the community on topics such as mental health and physical fitness, which we are examining to incorporate into our planning to ensure that our future events better meet the needs and interests of our community. We urge our community to let their voices be heard and participate in future discussions to best serve our members!

BRO



**Mujeres
Enlazadas
por Sangre**

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 over **\$4,000**
to help us provide **SCHOLARSHIPS**
for our community members!

Amazon • Anonymous (3) • Matt and Hazel Borowsky • Marilyn Borowsky • Rachel Borowsky
Chevron • The Desai Family • Brenda Gonzalez • Sandra Green • Gloria Hernandez
The Iavicoli Family • The Kelly Family • Kendra Scott • Kroger • Sandra Knight
William and Judy Metscher • Microsoft • Matt Moyer and Rigo Garcia • Bob Numerof
Panda Express • Doris Quon • Jack Renauer • Jennifer Shields • United Way
David Warner • Michele and Doug Warner • Linda and Mike Queen • Shawn Whelan



Thank you to the City of Ventura for issuing a
proclamation on behalf of our community and promoting
awareness for those living with rare bleeding disorders!
We are so appreciative of Mayor Joe Schroeder for
proclaiming the month of March as Bleeding Disorders
Awareness Month.

*(pictured left: Executive Director Rigo Garcia and
Community Member Mia Castaneda-Layman proudly
showcase the proclamation for Bleeding Disorders
Awareness Month)*



HFSC WASHINGTON DAYS

Advocates from across the country joined the National Hemophilia Foundation in Washington, DC on March 9 to meet with legislators at the Capitol. Southern California was represented by eight community members, asking Congress to support continued funding of our Hemophilia Treatment Centers (HTCs) by the National Institutes of Health (NIH), Centers of Disease Control and Prevention (CDC) and Health Resources and Services Administration (HRSA). Additionally, HFSC asked our legislators to sign onto HR 830, also known as the HELP Copays Act. This bill would require health insurance plans to apply certain payments made by or, on behalf of, a plan enrollee toward a plan's cost-sharing requirements.

HFSC would like to thank Representative Judy Chu (D-28) for taking time to meet with our group personally and hear our stories! We also would like to thank Representative Nanette Diaz Barragan (D-44) for co-sponsoring HR 830.

Thank you to all our great advocates who made the trip to DC: Langston Brown, Karlyn Johnson Brown, Mia Castaneda, Rigo Manzo, Leslie Guevara, Ivan Giron, Rigo Garcia, and Casey O'Brien.



Jivi[®], now with up to **7 YEARS OF DATA.**

Talk to your doctor about the study.



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about the data at
JiviExtensionStudy.com

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WELCOME OMAR TORRES TO THE HFSC TEAM!

We are excited to welcome Omar Torres to the HFSC team as the Community Outreach & Engagement Coordinator. Omar is eager to connect and collaborate with individuals, families, and community leaders to best serve the bleeding disorders community. Though Omar recently joined HFSC on a professional level, Omar has been a member of the hemophilia community his entire life having been diagnosed with hemophilia at the age of 5. Omar has a tremendous passion for serving communities that are often overlooked and underrepresented.

Prior to joining HFSC, Omar was a Consumer Service Coordinator at the Inland Regional Center. He was responsible for assisting, advocating, and securing social services for individuals with qualifying Developmental Disabilities that fulfill their needs, goals, and strengths. Additionally, Omar has worked as a Therapeutic Behavioral Specialist for one of California's largest nonprofit behavioral & mental health agencies,

where he was responsible for providing strength-based interventions to address concerning behaviors among children and adolescents. Such experiences have allowed Omar to work closely with Medi-Cal, managed care plans, State and County agencies, behavioral health agencies, school districts, and local community leaders.

We are happy to have Omar join the team and continue to assist the community in his new role. You can reach Omar at omar@hemosocal.org.



SACRAMENTO LEGISLATIVE DAY

On March 21st, 2023, the Hemophilia Foundation of Southern California (HFSC) attended Legislative Day hosted by the Hemophilia Council of California (HCC) in Sacramento. Legislative Day is an important event where individuals, families, and allies of the bleeding disorders community across California come together to advocate for their needs and raise awareness about the challenges they face in accessing healthcare.

This year, HFSC attended Legislative Day to share the stories of community members living with bleeding disorders and advocate on issues that affect the bleeding disorder community. This included for the maintenance of programs such as California Children's Services (CCS) and the Genetically Handicapped Persons Program (GHPP). Both CCS and GHPP provide critical support to individuals with bleeding disorders, including access to specialty care, medications, and other essential health services.

The primary issues that HFSC and HCC were advocating for was the protection of patient assistance programs. Patient assistance programs are critical for individuals with bleeding disorders, as they help pay for expensive medications and treatments that are necessary to manage their condition.

Specifically, HFSC and HCC were advocating for the support and passage of proposed bill AB 874, which would protect patient assistance programs by banning the use of copay accumulator programs. Copay accumulator programs are a cost-saving measure used by some insurance plans and pharmacy benefit managers (PBMs) that prevent the application of copay assistance towards a patient's deductible or out-of-pocket maximum. This often leads to patients paying more out-of-pocket for their medications and treatments, making it harder for them to access the care they need. AB 874 would require health insurance plans and PBMs to apply any amount paid by the insured through copay assistance to the patient's deductible or out-of-pocket maximum. This would help ensure that patients with bleeding disorders can continue to access the care they need without having to worry about the financial burden of high deductibles and out-of-pocket expenses.

Throughout the day, HFSC met with the staff of assembly members and senators in the counties that HFSC serves. HFSC community members and staff shared their personal stories about serving individuals with bleeding disorders and how patient assistance programs have helped community members access the care they need. HFSC also discussed the importance of passing AB 874 and the impact it would have on the bleeding disorders community.

Legislative Day proved to be a successful event for HFSC and the bleeding disorders community. It provided a platform for individuals and families to come together, advocate for their needs, raise awareness about the challenges they face, and push for positive change. By actively participating in such events, HFSC continues to serve and advocate for important issues that affect the bleeding disorder community, including patient assistance programs and the passing of AB 874. Moving forward, HFSC will continue to advocate to ensure that individuals with bleeding disorders in California and across the United States can access the necessary care to lead healthy and fulfilling lives.

2023 ANNUAL WOMEN'S RETREAT

Ninety HFSC community members along with volunteers, staff, and sponsors gathered at the Marriott Irvine Spectrum on Saturday, March 18 to Sunday March 19, 2023 for our annual Women's Retreat. The day started off with participants visiting sponsor booths and making customized keychains as a memento of the weekend. During lunch, HFSC Executive Director, Rigo Garcia, presented "Mindful Moments" to give participants a way to bring themselves back to the present through mindfulness practices that can be done anywhere.

Participants then attended breakout sessions where they heard from Sandra Valdovinos Heredia (Mujeres Salud Mental and Women's Mental Health sessions), Dr. Doris Quon, Medical Director at Orthopaedic Hemophilia Treatment Center (Updated vWD Guidelines session), Dr. Nina Hwang, Pediatric Hematologist at Center for Inherited Blood Disorders (Treatment for Mild Hemophilia session), Mia Castaneda (Teen Self-Care Kit session), Annabelle Garcia, Community Education Specialist from Takeda (Women's Empowerment and Advocacy session), Lena Volland, Director of Education at the National Hemophilia Foundation (Finding Strength Through the Struggle session), Cassie Roque, yoga instructor (Molly's Yoga Break), and Dr. Terez Yonan, Adolescent Medicine physician at CHOC (Teen Rap Session). After a break, the ladies gathered for a reception and sponsor booths before dinner.

The dinner presentation and discussion, "Celebrating Connection in Our Hemophilia Community," was led by Cynthia N. Chavez, CoRe Manager at Sanofi. At breakfast on Sunday, participants heard from Marjorie Hunt, Medical Science Liaison, from Octapharma on "Women and Bleeding: A Deep Dive."

THANK YOU TO OUR WOMEN'S RETREAT SPONSORS!

PLATINUM



GOLD



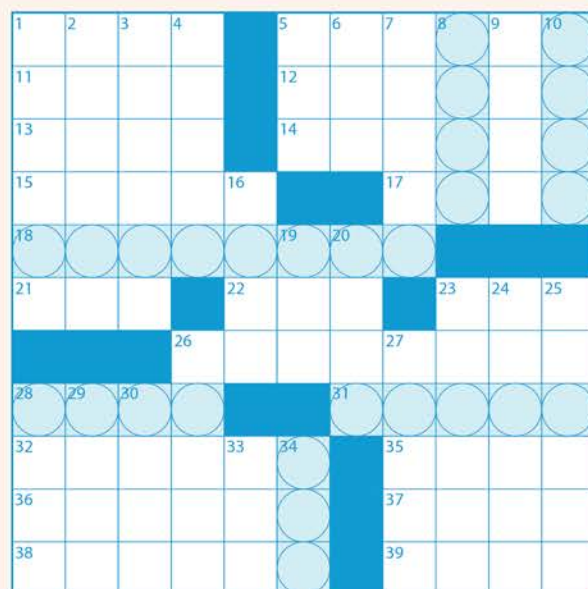
Thank you also to all our amazing volunteers: Lorrie LaCarra, Erika Clement, Linda Clement, Nicole Crook, Mesly Guzman, and Rosie Villalpando.



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. chasm, 11. Aden, 12. parish, 13. tore, 14. used to, 15. cruel, 17. nest, 18. HEMLIBRA, 21. yrs, 22. rue, 23. M.C.s, 26. passport, 28. zero, 31. three, 32. eyelid, 35. Crote, 36. anose, 37. tall, 38. lessen, 39. oles
Down: 1. catchy, 2. adore, 3. serum, 4. kneel, 5. CPU, 6. has, 7. arena, 8. side, 9. M51s, 10. shot, 16. lira, 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

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 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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MEDICAL ARTICLE SPOTLIGHT

STUDY FINDS MANY MOTHERS OF CHILDREN WITH HEMOPHILIA EXPERIENCE GUILT

HEMATOLOGY ADVISOR

February 21, 2023 by Vicki Moore, PhD



Researchers have found that some mothers of children with hemophilia (CWH) feel an increased sense of guilt regarding their child having this genetic condition, highlighting a possible need for support for mothers of CWH. The experiences of guilt and coping strategies in mothers of CWH were evaluated in a study with results reported in the journal *Haemophilia*.

"We determined 40% of mothers felt increased guilt overall, while up to 64% felt guilt for a specific reason," the researchers explained in their report.

The researchers sent an anonymous electronic survey to mothers of CWH. Mothers eligible to participate in the study could be carriers, confirmed noncarriers, or nonbiological mothers. The researchers used the Parent Experience of Child Illness tool to assess maternal guilt, and they used the PROMIS Parent Proxy for Life Satisfaction tool to assess perceptions of the child's life satisfaction, in addition to particular factors related to guilt and approaches to coping.

From a total of 291 possible recipients, 26% responded to the electronic surveys, resulting in 87 mothers of CWH who provided responses. Mothers in this analysis had a mean age of 41.6 years, and their affected children had a mean age of 13.3 years.

The researchers reported that mothers in this study population had perceptions of their child's life satisfaction that were not very different from the average population. However, increased overall guilt was reported by 40% of mothers. Common specific reasons for guilt that were expressed by mothers involved a sense of causing their child to experience pain through infusions or a sense of having given their child an X chromosome associated with hemophilia.

However, there were also factors that appeared to be associated with feeling less guilt. A sense of guilt appeared to decrease with age. Additionally, less guilt was felt by those who believed that the child had a high quality of life or those who underwent genetic counseling.

Social support, self-education, and forming ties with other mothers in support groups were common ways that mothers coped. The researchers also indicated that coming to terms with a child's hemophilia diagnosis was linked to improved emotional well-being among mothers. The researchers additionally pointed out that providers should not suggest that there is an expectation a mother would feel guilt.

"This is the first study that quantitatively examined the scope and extent of guilt in biological and non-biological mothers of CWH," the researchers wrote in their report. They concluded that immersion in the community provided social and educational benefits for mothers. They also noted that a sense of guilt had not been reported by the majority of mothers in the study, which they indicated was a sign of the adaptability and resilience of members of the hemophilia community.

Reference: Sheridan N, Thompson B, Lichten L, Coleman K, Sidonio Jr R. The emotional experience of mothers of children with haemophilia: maternal guilt, effective coping strategies and resilience within the haemophilia community. *Haemophilia*. Published online January 31, 2023. doi:10.1111/hae.14746

Article provided by the National Hemophilia Foundation



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