



Hemophilia Foundation
of Southern California

SUPER HEMO WALK

HFSC'S UNITE FOR BLEEDING DISORDERS WALK & HEALTH FAIR

November 4, 2023 • Whittier Narrows Park

www.uniteforbleedingdisorders.org/event/socal



LETTER FROM THE BOARD PRESIDENT

I cannot wait to see all of you this year at Whittier Narrows for our 15th Annual Superhero-themed Unite for Bleeding Disorders Walk & Health Fair.

Thank you all so much for joining me in registering and fundraising in support of our local Walk. Your donations fund much needed local initiatives such as Camp Blood Brothers & Sisters, College Scholarships, Advocacy and Access to Care, Educational and Support Programs, Emergency Financial Assistance, and Research. Thanks to your dedication and commitment to our community, we are able to continue to assist, advocate, and serve those living with bleeding disorders in Southern California.

A heartfelt thank you to all of you for such amazing and impactful support in helping HFSC continue to fulfill its mission.

Sincerely,
Rick Kelly, HFSC Board President



LETTER FROM THE EXECUTIVE DIRECTOR

The UNITE Walk fundraiser stands as a beacon of hope and unity within our community, serving as a vital lifeline that fuels the numerous essential programs and initiatives we hold dear. With every dollar raised, we unlock a world of possibilities, channeling these funds directly into our community programming. These programs, ranging from Camp Blood Brothers & Sisters to College Scholarships, Advocacy and Access to Care, Educational and Support Programs, Emergency Financial Assistance, and Research, are the bedrock of our shared mission.

Camp Blood Brothers & Sisters is a sanctuary where bonds are forged, and lifelong friendships are born. Scholarships pave the way for bright futures, ensuring that our young minds have the means to pursue their dreams. Advocacy and Access to Care empower our community to stand strong in the face of adversity, while Educational and Support programs provide invaluable resources to navigate the complexities of living with our condition. Emergency Financial Assistance offers a lifeline during times of crisis, and Research fuels the hope of a brighter future for all affected by our shared challenges.

The UNITE Walk fundraiser is not just about dollars and cents; it's about solidarity and the unwavering commitment of our community to uplift and support one another. It's a testament to the strength we find in unity, and it ensures that our vital programs continue to thrive, offering hope and assistance to all who need it. Together, we can achieve the extraordinary, and the UNITE Walk fundraiser is the embodiment of that collective spirit.

With sincere appreciation,
Rigo Garcia, HFSC Executive Director

Factor Club 2023

Factor Club members have raised \$500 or more for the Unite Walk in 2023 (as of 10/17/2023).

Thomas Barker	Asha Desai	Steve Iavicoli	Bob Numerof	Deborah Sazdoff
Michael Bennett	Laura Desai	Karlyn Johnson Brown	Joseph Olazaba	Omar Torres
Jane Brady	Rigo Garcia	John Kim	Perry Parker	Michele Warner
Rubuen and Julie Brizuela	Mike and Kristi Grob	Joshua Kim	Diana Parker	Shawn Whelan
Shin Chen	Grace Hernandez	Michelle Kim	Holger Peens	Elsa Raigoza
The Clement Family	Amelie Iavicoli	Richard Metz	Doris Quon	Valinda Ribadeneira



**Hemophilia Foundation
of Southern California**
FOR ALL BLEEDING DISORDERS

SUPPORTING 20 RARE BLOOD DISORDERS

Hemophilia A

Hemophilia B

Inhibitors

Afibrinogenemia

Factor II Deficiency

Factor V Deficiency

Factor VII Deficiency

Factor X Deficiency

Factor XI Deficiency

Factor XII Deficiency

Factor XIII Deficiency

ITP

Von Willebrand Type I

Von Willebrand Type II

Von Willebrand Type III

Glanzmann
Thrombasthenia

Storage Pool Disorders

Bernard-Soulier

Aplastic Anemia

Adhesion Disorders

WALK DAY INFORMATION

Agenda

9:30 am

Registration

Sponsor Booths, Health Fair, and Activity Time

11:00 am

Opening Ceremony

11:20 am

Superhero Scurry

11:30 am

Walk

12:00 pm

Lunch from The Habit Burger Grill Truck

12:45 pm

Awards Ceremony

Factor Club Winners

Top Fundraising Team

Top Fundraising Individual

Best Costume

Best T-Shirt





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WALK CO-CHAIR ELSA RAIGOZA

It is a great honor to serve as the 2023 Walk Co-Chair for such an amazing organization, the Hemophilia Foundation of Southern California (HFSC). My journey into walking for bleeding disorders is rooted in professional as well as personal experience. A significant turning point in my life occurred when I broke my ankle last year, an experience that was not only physically painful but also emotionally distressing. While I sat for hours working to distract myself from my pain, I was reminded of the importance of both the Foundation and of my role at a local HTC in advocating for and supporting the bleeding disorders community.

Having worked at CHLA for over 12 years, it is an honor to unite with HFSC and the SoCal bleeding disorders community in our unwavering commitment to bring about positive change and offer crucial support to those who need it most.

Thank you!

Elsa Raigoza, CHLA



WALK CO-CHAIR JACQUELINE CEJA

I am honored to be able to write this article to my beloved Hemophilia Foundation of Southern California. I grew up in Southern California specifically in the San Fernando Valley and now reside in Bakersfield, California. Both my father and my son have Hemophilia A.

Growing up I witnessed my dad in pain and the lack of access to his medicine and would think of how unfair things were for him to be able to access his medicine. I remember spending a whole day at the emergency room with him just to be able to get his factor infused. Multiple times the emergency room had no idea what Hemophilia was because

of how rare it is. They would have to get the factor shipped from other medical facilities because they didn't have it on hand. My father was also not aware of how crucial it was for him to receive his medication to prevent or cure joint bleeds. He would not go to the doctor to avoid the hassles and would get up with excruciating pain from a joint bleed in the morning and go to work without treating it. This caused many complications during his life.

In 2012, my son Matthew was born. I immediately knew in my heart he had Hemophilia and the fear that my son would go through the same struggles my father did was just not acceptable to me. I began doing research, learning, advocating, and being aware of things that I just didn't know before. It opened my eyes to many things that my father could have done differently. I took it upon myself to no longer view Hemophilia as a bad thing and to make sure my son knew his condition and not be ashamed of it as well as being aware of his own body. Matthew is now 11 years old and has learned to pay attention to his body and advocate for himself and make others aware around him about his condition. He currently self infuses and learned how to infuse thanks to funds raised for the HFSC Walk allowing him to attend the Painted Turtle Camp. He looks forward to every summer to be able to reunite with his fellow friends at the camp and feels so happy to be a part of the Foundation and also know there are other peers going through the same thing as him. This past summer his sister was able to attend camp for the first time and it was so magical for her to be able to be a part of something that her brother talks about all year. We walk to raise awareness as well as raise funds for children like Matthew and siblings, so they can experience the magic of camp as Matthew describes it.

Thanks to the Hemophilia Foundation for all you do! Thank you to all my family and friends for supporting us in our journey.

Jacqueline Ceja

THANK YOU TO OUR SPONSORS!

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Presenting Partners



National Community Partners



National Partner



National Virtual Partner



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Bronze Sponsors



Kilometer Sponsors



Ice Cream Sponsor





BE A HERO AND BID!

Bid High and Bid Often in our Online Auction to support
our Unite for Bleeding Disorders Walk! Items include...

Disneyland Tickets • Dodgers VIP Experience • Wine Tastings
Performance at Walt Disney Concert Hall • A Day at the Zoo

...and more! Scan the QR for more info!



CAMP BLOOD BROTHERS AND SISTERS AT THE PAINTED TURTLE

From July 16-21, HFSC Campers enjoyed a spectacular week at the Painted Turtle for Camp Blood Brothers and Sisters. It was a week of fun, making new friends, meeting old friends, and spending time as a community. From challenging themselves on the ropes course, horseback riding, fishing, learning archery, and competing in camp games, campers were never bored!

Congratulations to all our Big Stick Award Winners this year!

Independent completion of peripheral self-infusion from start to finish

Langston Brown
Jonathan Lopez-Rodriguez
Carlos Juarez

Ioan Angel Suarez
Yahir de Jesus Ochoa
Sophia Horta

Matthew Arias Gonzalez
Lucas Brolezi
Milo Burke

Carlos Santa Cruz
Frankie Merino
Nataly Miller-Hooks
Andrew Casas



Finally, thank you to everyone who raised funds at our walk in 2022 to ensure our campers could enjoy camp this summer. We are so thrilled every year for the opportunity to partner with the Painted Turtle to bring everlasting change and impact to our kids with rare inheritable bleeding disorders. For more information about camp, eligibility, and how to volunteer, please visit: www.thepaintedturtle.org.

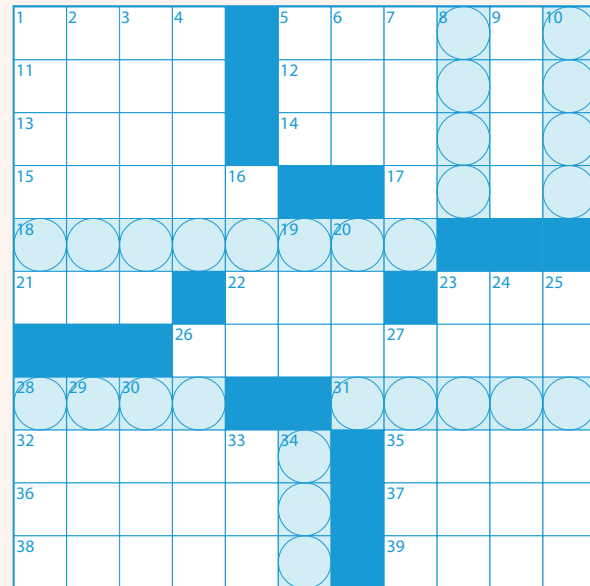
Thank you to our corporate sponsors of Camp Blood Brothers and Sisters!

Cabin Sponsor: Takeda; Archery Sponsors: Bayer, CSL Behring, Novo Nordisk, Sanofi; Camp Sponsors: CVS Specialty, Grifols, Pfizer, Stater Bros

CAMP BLOOD BROTHERS AND SISTERS AT THE PAINTED TURTLE



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 (various insurance plan types) from September 2021–August 2022 (refreshed November 2022), accounting for prophylaxis use 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

- 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*

† Number of people with hemophilia A treated as of October 2021.

SOLUTIONS

Across: 1, cask, 5, chasm, 11, Adam, 12, parish, 13, ore, 14, used to, 15, cruel, 17, nest, 18, HEMMELBURA, 21, yrs, 22, tree, 23, MCS, 26, Clossport, 28, zero, 31, three, 32, eyelid, 33, Cress, 36, anise, 37, tall, 38, lessens, 39, oles **Down:** 1, catchy, 2, adorer, 3, sermons, 4, kneel, 5, CPU, 6, has, 7, arena, 8, side, 9, M51, 10, shot, 11, lira, 19, bus, 20, rest, 23, mortal, 24, Creole, 25, steels, 26, polos, 27, photo, 28, zeal, 29, Eyre, 30, Reis, 33, CSE, 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.
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Revised: 03/2023



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2022 HFSC HALLO-WALK: UNITE FOR BLEEDING DISORDERS WALK



Thank you so much for your support of HFSC's 2022 Unite for Bleeding Disorders Walk!



Ian Corona

Patient advocate

About Ian

Ian is a Novo Nordisk Rare Blood Community Liaison who loves exploring the great outdoors and serving his community. After having twin sons born with severe hemophilia B, Ian immersed himself in their care and learned as much as possible about hemophilia.

Connect with Ian

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Rare Blood Community Liaison

CA, NV, HI

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HFSC EVENTS CALENDAR 2023

- November 28** **Riverside Snowflake Dinner**
Riverside, CA
- November 30** **Monterey Park Snowflake Dinner**
Luminarias
Monterey Park, CA
- December 3** **Bakersfield Snowflake Dinner**
Bakersfield, CA
- December 4** **Santa Barbara Snowflake Dinner**
Harry's Plaza Café
Santa Barbara, CA
- December 5** **Burbank Snowflake Dinner**
Burbank, CA
- December 6** **Rancho Cucamonga Snowflake Dinner**
Rancho Cucamonga, CA
- December 7** **Lancaster Snowflake Dinner**
Lancaster, CA
- December 13** **Orange County Snowflake Dinner**
Orange County, CA

**SEE YOU
IN 2024!**

5 REASONS TO GIVE TO



**Hemophilia Foundation
of Southern California**



GUARDING THE U.S. BLOOD SUPPLY

80% of all people with severe hemophilia were infected by blood based medicine tainted by HIV in the 1980's. Thousands died. Due to this tragedy, we remain prime advocates and watchdogs of the blood supply to ensure blood safety nationwide.



RARE DISEASE ADVOCATES

1 in 10 Americans are affected by a rare disease the majority of whom are children. Hemophilia Patient Advocacy groups are one of the most well-organized and when we fight for our rights such as access to rare disease specialists, all those in the rare disease community benefit!



HEALTH INSURANCE ACCESS

HFSC advocates for access to health insurance on both the federal and state level. We constantly have a handle on proposed legislative changes that affect all. As a result of this hard work, all people who need and care about health insurance access can benefit!



GENE THERAPY AND INNOVATION

Gene Therapy may be the key breakthrough in providing a cure to many rare conditions that have no treatment. Gene therapy trials in hemophilia are well underway and this research can provide answers for other diseases.



HELPS EARN RESPECT

Donations can help you earn respect in many areas. Philanthropy is a noble act that reflects a good heart. It earns you respect of your peers, immediate community and broader society.

Unite
for Bleeding Disorders



There's still time to donate! Donations are accepted until 12/31/2023. Visit uniteforbleedingdisorders.org/event/socal or send donations to Hemophilia Foundation of Southern California 959 E. Walnut Street, Suite 114, Pasadena, CA 91106. Please note the donation is for the Walk.

YOUR DONATION MAKES A DIFFERENCE

100% of all individual donations raised go directly toward HFSC's services and programs.



Camp Blood Brothers and Sisters

Through the funds raised at the Walk, we can send children to Camp Blood Brothers and Sisters at The Painted Turtle at no cost to their families. At Camp, children learn how to self-infuse, participate in hands-on activities, and make friends with other children with bleeding disorders.



Emergency Financial Assistance

HFSC's Emergency Financial Assistance program is available to help families and individuals in the bleeding disorders community in one-time, emergency situations. As of early October 2023, HFSC has provided a cumulative financial support of \$9,649.07.



Medical Alert ID

HFSC provides free Medical Alert IDs to community members with bleeding disorders. As of October 2023, HFSC processed a total of 142 Medic-Alerts with a cumulative cost for the year of \$5,153.20



Scholarships

HFSC offers three scholarships to community members pursuing secondary education at a college, trade or vocational school, or continuing education classes. In 2023, HFSC was proud to award 14 scholarships for a total of \$13,500.00, which was an increase from past years.



Advocacy and Access to Care

HFSC participates in Federal advocacy during Washington Days in Washington D.C., and State advocacy with the Hemophilia Council of California's Future Leader's Program in Sacramento. Through funds raised, HFSC is able to send community members to represent their cities and speak with their legislators about important legislation.



ALTUVIIIIO™
Antihemophilic Factor (Recombinant),
Fc-VWF-XTEN Fusion Protein-ehf

SWITCH IT UP with ALTUVIIIIO™

Sanofi Community Relations and Education (CoRe) Managers are dedicated professionals who can provide personalized education about ALTUVIIIIO, and point you toward helpful support and resources.



CONNECT WITH
YOUR CoRe TODAY



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**Hemophilia Foundation
of Southern California**

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**Hemophilia Foundation
of Southern California**

Happy Anniversary!



**YEARS OF SERVICE
1954-2024**

We are looking forward to celebrating our 70th anniversary with you in 2024! If you are interested in joining the committee to help us plan this milestone, please contact Rigo Garcia, Executive Director, at rigo@hemosocal.org!