

# HEMOPHILIA ACTION

**A PUBLICATION OF THE HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA**

VOLUME 17 | ISSUE 3 | SUMMER | 2021

## PERRY PARKER INVITATIONAL

A heartfelt thank you to Perry Parker for hosting the Parker Invitational, a golf tournament in Pebble Beach, raising nearly \$15,000 for HFSC!

The event took place from May 31 - June 4 and included a full field of senior golf professionals from around the globe and their 3-man amateur teams. Players enjoyed a practice round on opening day, tee prizes, a welcome dinner with guest speakers and, of course, some healthy competition throughout the week!

Thank you to everyone who attended and supported this event! We are so appreciative of Perry for raising critical funds for the bleeding disorders community. Next year's event will take place May 30-June 3, 2022. If anyone is interested in playing or volunteering, Perry can be reached at [perryparkergolf@gmail.com](mailto:perryparkergolf@gmail.com).



Advocacy: Rigoberto Manzo



Advocacy: Mia Castaneda



Volunteer: Karla Reynado Arce

**2021 HFSC  
Award  
Winners**



Fundraiser: Iavicoli Family



Medical Professional:  
Dr. Gavin Roach



Medical Professional:  
Erika Bocanegra



Volunteer: Michua Family

## 2021 VIRTUAL FAMILY INFO DAY AWARD WINNERS

# THANK YOU DONORS

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## 2021 CALENDAR

**Community Dinner:**  
**Orange County, CA**  
October 6

**Shaka Surf Fest**  
**Santa Monica, CA**  
October 9

**BRO Dinner**  
**Whittier, CA**  
October 20

**Hemophilia Federation of America,**  
**Virtual Symposium**  
**(Register at [www.hemophiliafed.org](http://www.hemophiliafed.org))**  
October 18 - 28

**Cena del Grupo de Mujeres Enlazadas**  
**conmemorando el Día de los Muertos**  
**Downey, CA**  
November 2

**13th Annual SoCal Unite Walk**  
**LA Coliseum, Los Angeles, CA**  
November 13

## HEMOPHILIACTION

is published quarterly by

**The Hemophilia Foundation**  
**of Southern California**

## In Memory

Hector and Martha Guevara, in memory of Pedro Guevara

## In Honor

Harry & Juanita Boessler, in honor of Tyler, Abby and Michael  
Jane Brady, in honor of Amelie Iavicoli

*Donations made between 4.1.21 to 6.30.21*

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## A LETTER FROM THE BOARD PRESIDENT

Last year, the Board of Directors met to discuss the strategic direction of the Foundation. Two major changes were made. First, we shortened our mission statement and changed it to: "Improving the quality of life and building community for those living with inherited bleeding disorders in Southern California." Next, we created a list of our core values that we believe symbolizes our organization and guides our decisions and vision. These include: Passion, Service to Community, Teamwork, Integrity, Transparency and Diversity and Inclusion. Finally, we decided to create a strategic vision for the next few years which included: first, train and equip the Board of Directors to lead the organization. Second, ensure the Foundation maintains financial sustainability. Third, create a new marketing

plan to update our existing look and feel and provide for greater engagement. Fourth, maintain an excellent working staff who are supported in all areas and finally, create partnerships with other rare disease organizations to ensure we are educated with the latest tools needed to advocate on your behalf! The Board also decided to invest in local research to make a greater impact on the future of our bleeding disorders community. More updates to come! I hope that you and your family have been staying safe and healthy throughout the pandemic and, as always, please contact me if you have any questions. - Rick Kelly, MBA

## A LETTER FROM THE EXECUTIVE DIRECTOR

It's been a long time since we saw many of you. There are some who are facing hardship and challenges especially with the start of a new school year. I want to encourage you to stay courageous and strong; it's already in our blood for we are a community of resilience and have already overcome so much! Hopefully we will begin having live events outdoors beginning with our surf event (one of my favorites!) and the 13th Annual Unite Walk. We chose the LA Coliseum because of our fantastic theme, "Let the Games Begin: Olympics!" You are all gold medal winners in our minds. Whether you bring \$1 or \$100, I hope you can join us because we just want to SEE you. On the advocacy side, we issued a letter supporting several mental health bills as well as for AB 347, a Step Therapy Reform bill. We continue to fight to ensure access and protection to our rare bleeding disorder community!

I sincerely hope that you are all doing well and, as always, please reach out to me anytime at 626-765-6656 or [michelle@hemosocal.org](mailto:michelle@hemosocal.org). - Michelle Kim, Esq.





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#### 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**.

**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,  
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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: 10/2018



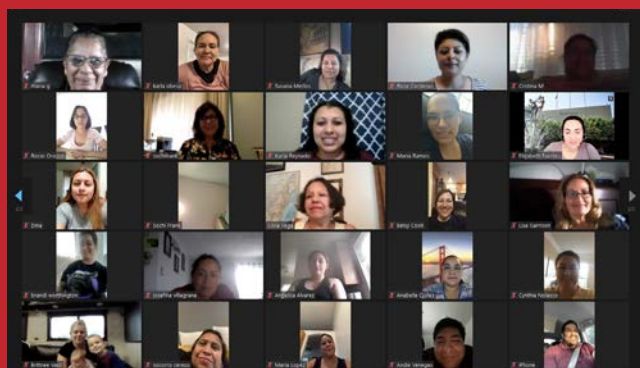
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## BRO MEETING: BLEEDERS REACHING OUT

Bleeders Reaching Out (BRO) continues to build unity by meeting virtually and providing mutual peer support. We hosted two amazing sessions in April and June. During the first meeting on Wednesday April 21, Dana Francis, Clinical Social Worker II, UCSF, presented on dealing with Covid isolation and the men were able to share and discuss their own personal tips. All men received an ESPN messenger bag with the BRO logo. On June 16, CSL Behring sponsored the meeting with Pro Golfer Perry Parker presenting on overcoming stumbling blocks and living life to its fullest. All the men attending received a Nike golf shirt with the HFSC logo. Hopefully we'll be able to play golf in those shirts soon.



## HEMOPHILIA 101: COMMUNITY DINNER

HFSC community members had the pleasure to hear from Silvia Vega and Shirley Romano Wycoco and learn about the basics of Hemophilia. With new babies being diagnosed each year, it's important to continually present this information to newer families. We were pleased to see over 40 attendees and thank Bayer for their support of this important program.

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Scan the QR code to learn more  
about PK at [UnderstandingPK.com](https://UnderstandingPK.com)

PK; Pharmacokinetics

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# 2021 EMPOWERMENT FORUM & WORLD HEMOPHILIA DAY

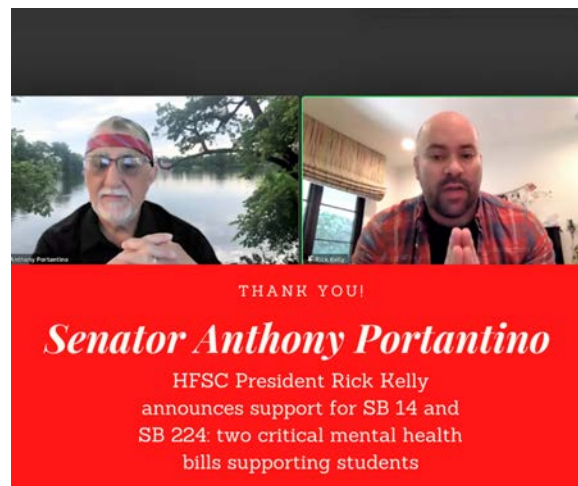
On Saturday, April 17, 2021, HFSC hosted its annual emPOWERment Forum and World Hemophilia Day celebration with over 130 attendees participating virtually, all wearing red, in honor of Bleeding Disorders Awareness!

Senator Anthony Portantino kicked off the day urging us to participate in advocacy and highlighting mental health needs and challenges. HFSC Board President Rick Kelly followed up by announcing HFSC's support for SB 14 and SB224 (mental health support for students) and thanked the Senator for his many long years of support.

The National Director of the World Federation of Hemophilia's (WFH) Jennifer Laliberte zoomed in from Canada to share about WFH's global efforts and to moderate a fantastic panel of women who are making huge impact: Megan Adediran, Executive Director of the Hemophilia Foundation of Nigeria, and Minerva Cruz Ramirez, the President of the Federación de Hemofilia de la Republica Mexicana, AC.

Next, National Hemophilia Foundation's President and CEO, Dr. Len Valentino, gave a comprehensive and exciting future outlook in the area of research and an update on COVID vaccines. Finally, HFSC highlighted all the advocates this year who lobbied at Washington Days and Legislative Days, also hearing from Rigo Manzo who helps to lead the BRO group, and Teen Leader, Mia Castaneda-Layman.

A huge thank you to our board, sponsors, and all of our wonderful volunteers!



A special thank you to our Platinum Sponsor



And Gold Sponsors





## FUTURE LEADERS MAKE A VIRTUAL IMPACT

This past May, the Hemophilia Council of California (HCC) hosted its Future Leaders program in partnership with its four founding members including HFSC. The goal of the program is to train and inspire young people in the vitally important work of advocacy. While the teens couldn't gather in person, HCC was pleased to host 18 Future Leaders for a 7-part webinar series that included 10 guest speakers, a pizza party, cookies and most importantly the opportunity to share their bleeding disorders stories with CA Legislators.

Students aged 14-22 participated in a story telling workshop, practiced sharing their story, and learned about advocacy, the legislative process and policy issues currently facing the bleeding disorder community. They also heard from guest speakers who work in the legislature and in public policy and learned about a variety of internship and leadership programs which they could apply for to further their interest in policy and advocacy.

Naomi Giron, Ivan Giron, Jr., Ilusion Perez, Haylee Slonaker, Vijaya Prathigudupu, Asrita Prathigudupu, Bailey Martinez and Luke Kim represented Southern CA as Future Leaders on Legislative Day where 50 advocates met with more than 30 legislators in virtual meetings to advocate for budget requests important to the bleeding disorders community among other things. Great job everyone!

*Hemophilia Council of California's Mission: To improve access to care and treatment options in order to advance the quality of life for people with bleeding disorders thorough advocacy, education, and outreach in collaboration with its founding member organizations. For more information visit: [www.hemophiliaca.org](http://www.hemophiliaca.org)*



## ANNUAL WESTERN STATES REGIONAL CONFERENCE

The Orthopaedic Hemophilia Treatment Center hosted the hybrid Region IX conference this year where brilliant and dedicated medical minds came together for 3 days to discuss best practices and the best care for us. Topics included alternative pain management, women and bleeding disorders, sports and bleeding disorders, and non-factor replacement therapies. Additionally, a critical discussion ensued around Hemophilia Treatment Center (HTC) sustainability. Costs are increasing and funds are decreasing to support these important comprehensive care centers. It's vital to the well-being of patients to ensure their continued viability. More to come on this important topic. Want to locate an HTC, but don't know how? Call Cynthia, HFSC's Outreach Manager, at 626-765-6656.



# Cómo lidiar con la hemofilia en familia:

## Sugerencias para manejar la dinámica familiar



Si desea obtener más información, visite [b2byourvoice.com](http://b2byourvoice.com) para descargar el archivo *Hemophilia B: A Family Perspective (Hemofilia B: Una perspectiva familiar)*.

Este contenido es posible gracias a Pfizer.

### La hemofilia afecta a toda la familia

A pesar de las mejoras en el manejo médico de los trastornos hemorrágicos, criar a un niño con hemofilia sigue afectando la vida de todos en la familia. Es importante ocuparse de las necesidades de los cuidadores y familiares, como también reconocer de qué manera un diagnóstico de hemofilia altera la dinámica familiar.<sup>1</sup>

La hemofilia es un trastorno complejo que requiere tratamiento de por vida. Si la hemofilia es algo nuevo en la familia, puede haber sentimientos de incertidumbre sobre cómo lidiar con el manejo diario. En particular, infundir el factor al principio puede ser perturbador para el niño y estresante para el cuidador que se enfrenta a desafíos en el proceso.<sup>1</sup>

**“Una cosa que aprendimos fue que crecer es un proceso de aprendizaje para todos los niños, tengan o no hemofilia”.**

— Jill L.

Madre de dos hijos con hemofilia B

### Disciplina y límites

Es importante para los padres y otros cuidadores apoyarse entre sí en el cuidado diario de sus hijos, incluyendo hablar sobre las emociones y superar juntos los desafíos relacionados con la hemofilia.<sup>2</sup> Algunos de estos desafíos puede incluir aplicar disciplina y establecer límites. A menudo se les recomienda a los padres y cuidadores que se ocupen de estos problemas de la misma forma en que lo harían con niños a quienes no se les haya diagnosticado un trastorno hemorrágico.

### Algunas sugerencias de la National Hemophilia Foundation que pueden ayudar a cuidar de un niño con hemofilia incluyen<sup>3</sup>:

- Elogie a su hijo cuando informe de un sangrado a un cuidador.
- Reafirme que tener un trastorno hemorrágico que requiere tratamiento no es un castigo.
- Converse abiertamente sobre los posibles efectos del comportamiento y las actividades.
- Nunca castigue a su hijo por el hecho de tener un sangrado.

Una preocupación importante que los padres o cuidadores pueden enfrentar es saber cuándo un niño tiene un sangrado. En algunos casos, los sangrados pueden ser difíciles de identificar, ya que un niño podría exhibir una o más de las siguientes señales o síntomas de una hemorragia muscular<sup>4</sup>:

- Mantener una parte del cuerpo en una posición incómoda o estar renuente a usar esa parte del cuerpo.
- Quejarse de dolor o una sensación de hormigueo en el área lesionada.
- El área lesionada se siente caliente, hinchada o firme al tacto.

Es importante reconocer que cuidar de un niño con hemofilia puede crear cambios a los que la familia debe acostumbrarse. Las modificaciones en el estilo de vida son parte de la convivencia con la hemofilia y, en ocasiones, estos cambios se extienden a toda la familia. No obstante, estos ajustes representan oportunidades para un cambio positivo a través del aprendizaje y autoconocimiento.<sup>5</sup>

**Referencias:** 1. Beeton K, Neal D, Watson T, Lee CA. Parents of children with haemophilia—a transforming experience. *Haemophilia*. 2007;13(5):570-579. 2. Wiedebusch S, Pollmann H, Siegmund B, Muthny FA. Quality of life, psychosocial strains and coping in parents of children with haemophilia. *Haemophilia*. 2008;14(5):1014-1022. 3. National Hemophilia Foundation. Steps for Living website. Discipline. [www.stepsforliving.hemophilia.org/first-step/family-life/discipline](http://www.stepsforliving.hemophilia.org/first-step/family-life/discipline). Consultado el 12 de julio de 2019. 4. Rivard G-E, Blanchette V, Hilliard P, Mulder K, Zourikian N. Management of bleeds. In: *All About Hemophilia: A Guide for Families*. Montréal, Québec: Canadian Hemophilia Society; 2010: 4-1-4-32. 5. Cassis FRMY. *Psychosocial Care for People With Hemophilia*. Montréal, Québec: World Federation of Hemophilia; 2007.



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## COMMUNITY SPOTLIGHT: LARRY HAMMERNESS

Born and raised in San Jose, Larry discovered his love of the water at a very young age, visiting a beach nearby his home. His appreciation for swimming quickly evolved into his passion for the sport of surfing, which he mastered at the age of 13.

Larry moved to Venice Beach in the 1990s and continues to surf as often as he is able, despite any setbacks he may encounter, due to his severe hemophilia.

Diagnosed with a bleeding disorder at birth, Larry has faced many challenges throughout his life, including multiple surgeries on his target joints, due to bleeds in those areas. He most recently had his right gas pedal joint fused, as well as the side-to-side joints in both ankles fused. He also has had knee replacement surgery, but does not let any of that deter him from getting on his board and riding the waves. Larry is thankful he can remain active and advocates that "anyone with a bleeding disorder could benefit by staying active, especially in the water."

His turning point was learning how to self-infuse Factor at the age of 12, which allowed him both the freedom to infuse before any activity he wanted to try, or to infuse if he happened to get injured. Larry's advice to younger hemophiliacs is to stay active, whether your passion is sports or the arts, as these pursuits can help greatly with your mental health and well-being.

In addition to surfing, Larry enjoys building bicycles, playing guitar and drums, and has even tried his hand at skiing. He attended college for fine arts and is a photographer by trade, having discovered this interest in 7th grade.

He is grateful to be part of our Southern California bleeding disorders community and would be open to sharing with the younger generation about his past experiences with a bleeding disorder and with surfing, should anyone be interested in learning more!



## COMMUNITY DINNER SPONSORED BY TAKEDA

We had an amazing community dinner on June 9, 2021 and full house for the presentation, "What is Healthy Aging with a Bleeding Disorder," sponsored by Takeda. Those in attendance were able to learn about chronic pain and advance directives. Thank you to Susana Escojido for your wonderful presentation and discussion.



## VOLUNTEER SPOTLIGHT: RON STAAKE, HFSC TREASURER AND BOARD MEMBER

It has been a privilege and honor to serve on the Board of HFSC for the last five years. A couple of years ago I was elected to the role of Treasurer, a position I have thoroughly enjoyed and take great pride in. More than anything however, it has been a wonderful experience working closely with Michelle Kim, HFSC's Executive Director, and the rest of the Foundation's Board and Staff. Their dedication and passion, working to improve the quality of life for people with many variations of bleeding disorders, their caregivers, and their families has been truly inspirational.

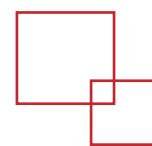
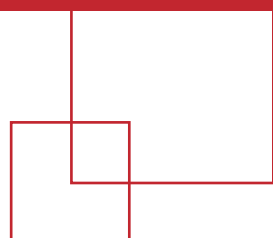
In 1959 I was born with severe Hemophilia A. It has been amazing for me to observe and be a part of the tremendous changes that have occurred during the past 60 years. As a young active boy, when a joint bleed occurred, the process necessitated my parents driving me from Redondo Beach to Orthopedic Hospital for treatment. Once there, very large bottles of frozen plasma were mixed and transfused. This entire process from bleed recognition, to finishing with the transfusion, would take most of the day. Needless to say, the damage to my joints was unfortunately unavoidable. Now, the entire process takes 5 minutes. It is a joy to see how young hemophiliacs are able to treat themselves quickly at home, or anywhere, and be able to lead happy, healthy, and productive lives.

I have been married for 33 wonderful years. We have two beautiful and talented daughters, ages 27 and 23. I enjoyed a successful career in Financial Management and was able to retire early and now fill my days with volunteering, golf, skiing, exercising, biking, and most enjoyably, slowly venturing out and travelling in this challenging Covid environment. I mention all this because I have heard from more than a few parents about their fears of having their child do too much in the way of activities. While I highly encourage taking appropriate safety precautions, I feel it is important for young people with a bleeding disorder, such as Hemophilia, to maintain joint strength by remaining prudently active. I believe (and have personally experienced) how incredibly important this is for both physical and mental health.

I look forward to continuing to provide assistance on the Board and within the bleeding disorder community. I also look forward to meeting with you at the many well-planned, fun and educational events organized by the amazing staff and management of HFSC. Please feel free to reach out to me with questions, concerns, comments, or just to say hello through the HFSC office and most importantly, please stay healthy and safe!



Do you have questions about Covid-19 or about vaccinations? Check out the guidelines released by the National Hemophilia Foundation (NHF) here: <https://bit.ly/3AAYkD8>



# HFSC OLYMPICS: LET THE GAMES BEGIN!

## 13TH ANNUAL UNITE FOR BLEEDING DISORDERS WALK



Join us on Saturday, November 13, 2021, for our Olympics-themed Walk at the LA Coliseum, where we will walk together in support of all those affected by bleeding disorders in Southern California. Attendees will also enjoy a fun-filled program where we will highlight teams, award prizes, play games, hear from our sponsors, and more!

Register today at [www.uniteforbleedingdisorders.org/event/socal](http://www.uniteforbleedingdisorders.org/event/socal) to create a team, and begin recruiting your family, friends and co-workers to join you. Every dollar raised will directly support HFSC's programs, including emergency financial assistance, scholarships, advocacy and access to care, education, research, and Camp Blood Brothers & Sisters.

Don't forget to dress up in your favorite Olympic-themed outfit for a chance to win a prize for best costume!

Questions? Please reach out to:

Michele Warner  
Director of Development  
[mwarner@hemosocal.org](mailto:mwarner@hemosocal.org)



Use the QR code above to register now!

Thank you for your support!



NOVEMBER 13, 2021  
LA MEMORIAL COLISEUM

**"GO FOR THE GOLD" FUNDRAISING INCENTIVES**

**\$25**

EARN YOUR OFFICIAL 2021  
UNITE FOR BLEEDING DISORDERS EVENT T-SHIRT!

EVERY WALKER WHO RAISES \$25 OR MORE WILL RECEIVE THE 2021 COLLECTIBLE SHIRT!

**\$250**

CAMPFIRE COFFEE MUG

**\$500**

FAMILY TOTE BAG\*\*

**\$1,000**

TECHNOLOGY KIT

**\$2,500**

JACKET & VIP TENT\*\*\*

\*\* Every walker who raises \$500 or more also becomes part of the Factor Club and receives an exclusive finishers medal!

\*\*\* Raise \$2,500 or more and receive an exclusive VIP Tent on walk day!

Gifts are not cumulative; only one item is awarded to each fundraiser, based on the total funds raised by one month post the event. Jackets are available in men's and women's sizes.





# 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](https://ortho-institute.org/hemophilia)



## 2021 VIRTUAL FAMILY INFO DAY

HFSC hosted an exciting Family Info Day 2021: Summer Kick Off with over 100 families! This extraordinary event began with a presentation of stories from a courageous and talented plenary panel: Amelie, Bailey, Fray, Carlos and Matt and an equally talented hematology team: Dr. Doris Quon and Dr. Gavin Roach who moderated the panel. Prior to the event, parents submitted words to describe their concerns for their children (see word map) and the panelists responded and allayed many fears. We are so ever thankful for our vibrant community who continuously supports one another and endeavors to listen and care. Our breakouts included a discussion on re-entering society after covid isolation with Dr. Bloom, Joint Health, Gene Therapy Jeopardy, and Overcoming Adversity in Spanish. HFSC also announced its 2021 Unite Walk Theme: Olympics!

As always, an army of supporters truly made this special day possible including Hemophilia Federation of America and our Platinum Sponsor: Takeda. Also, Gold Sponsors: BioMarin, Genentech, Octapharma and Pfizer! Congratulations to our annual award winners!

Finally our deepest gratitude as always to volunteers: Paul, Linda and Erika Clement, Betsy Cook, Rosie Villalpando, Maya Luna, Rose Cardenas, Keely King and our incredible Board of Directors including presenters: Rick Kelly, Bob Numerof, Sandra Corey Knight, and Brian Iavicoli. All attendees were treated to a box full of educational information and HFSC sunglasses and beach blanket!

### Platinum Sponsor



### Gold Sponsors



HFSC's 2021 Awards were announced during our Family Information Day meeting on May 21. Our community is only successful with help from dedicated volunteers, fundraisers, advocates, and medical professionals. Thank you again for all you do to support HFSC, and congratulations!

### Volunteer of the Year

#### Karla Reynado-Arce

Karla is a newer volunteer who stepped in during our virtual events to moderate sessions and breakouts, and also helped pack up boxes this year during the pandemic.

#### Michua-Puente Family

The Michua-Puente family have been helping out since 2016 and are often the first to arrive and last to leave at our events. Even with the pandemic, their family donned masks and have helped pack countless boxes for our virtual events.

### Fundraiser of the Year

#### Amelie's GT Striders (Brian, Elena, and Amelie Iavicoli)

Amelie's GT Striders have been participating in the Unite Walk since 2017. In 2020, Elena Iavicoli was our Walk Chair, and she and her husband, Brian, and daughter, Amelie, shared their stories and raised a huge amount for the bleeding disorders community through creative fundraisers including selling Amelie's artwork and offering to walk neighbors' dogs.

### Advocate of the Year Award

#### Mia Castaneda Layman

One of HFSC's Teen Leadership graduates, Mia has participated in Washington Days 3 times as well as developed relationships with her legislators through passionately telling her story. Mia also has acted as a mentor and moderator for our teen sessions at the HFSC Women's Retreat and is a fantastic role model for our young leaders.

### Advocate of the Year Award (continued)

#### Rigo Manzo

Rigo is a member of the Hemophilia Council of California's advocacy committee and represented HFSC as a mentor to the teens during the Future Leaders program. Rigo also helps to lead the BRO group, Bleeders Reaching Out, one of our community groups composed of men with bleeding disorders and fathers/father figures of children with blood disorders.

### Medical Professional Award

#### Dr. Gavin Roach

Dr. Roach is a pediatric hematologist with Orthopaedic HTC and the Director of the pediatric hematology program at UCLA. Despite his extremely busy schedule, Dr. Roach has made it a priority to carve out time each year for the last 5 years to spend his vacation time volunteering with The Painted Turtle's Well Shell at our Camp Blood Brothers and Sisters.

#### Erika Bocanegra

Erika is a senior clinical social worker at Orthopaedic HTC. She provides psychosocial support, counseling, and education to children and adults as part of a lifespan approach. She is passionate about serving our community and always answers with a resounding YES when asked to speak at our many programs and events.





# STUDY LOOKS AT NEURAXIAL ANESTHESIA AND POSTPARTUM COMPLICATIONS IN HEMOPHILIA

Findings from a recently published study in the *Journal of Anesthesia* suggest that pregnant patients with hemophilia whose factor VIII or IX levels drop below 50% at the time of receiving neuraxial anesthesia are more likely to experience postpartum complications. Neuraxial anesthesia refers to the administration of local anesthetics and analgesia to targeted locations in the spinal area. Epidurals are a commonly utilized form of neuraxial anesthesia, often used as a method of pain relief during labor.

Investigators were led by Brandon Togioka, MD, Associate Professor, Department of Anesthesiology and Perioperative Medicine at the Oregon Health & Science University in Portland. Togioka and his colleagues conducted two sets of literature reviews in October 2019. The first review, which included 13 articles, encompassed individual case reports and case series that described neuraxial techniques in patients with hemophilia—regardless of sex, age, or pregnant status. The second review, which included 19 articles, looked for case reports and series that outlined bleeding outcomes among pregnant patients.

Findings from the first review showed that 3 of 134 patients had neuraxial hematoma with paraplegia (paralysis of the legs and lower body). All three of these patients presented with a factor level of 1%. The second review showed that out of 2,712 deliveries, postpartum hemorrhage occurred in 193 patients (7.1%), which necessitated blood transfusion in 60% of these patients. Overall, postpartum bleeding complications were nearly “twice as likely” where factor levels were below 50%.

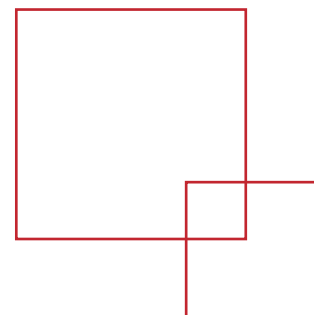
“In summary, we found low level evidence (Level 4) that factor VIII and IX levels should be greater than 50% for delivery and neuraxial techniques. In our review of 134 neuraxial placements and 2,712 deliveries, neuraxial hematomas were found with a factor level of 1% and hemorrhagic complications were higher when factor activity was <50%,” explained Togioka and his fellow authors. “Therefore, factor levels should be assessed and increased above 50% prior to neuraxial technique and delivery.”

The review, “Delivery and Neuraxial technique Outcomes in Patients with Hemophilia and in Hemophilia Carriers: A Systematic Review,” was published March 2021 in the *Journal of Anesthesia*.

Please note that earlier this year, NHF’s Medical and Scientific Advisory Council (MASAC) issued MASAC Document #265 which provides recommendations for the diagnosis and management of women with bleeding disorders during pregnancy, labor, and delivery. It also addresses the critical postpartum period with specific treatment recommendations designed to both mitigate the risk of bleeding-related complications in women and to enable the early diagnosis of affected infants. The document also does include recommendations on the appropriate use of neuraxial anesthesia.

View and download MASAC Guidelines for Pregnancy and Perinatal Management of Women with Inherited Bleeding Disorders and Carriers of Hemophilia A or B.

Source: *Hematology Advisor*, April 6, 2021





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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)!**

A photograph of a surfer in a black wetsuit riding a wave. The surfer is seen from behind, with their arms outstretched. The wave is breaking, creating white foam. In the background, another person is visible in the water. The sky is a clear, pale blue.

  
TIME FOR A BEACH PARTY!

**3RD ANNUAL  
SHAKA SURF FEST**

**Santa Monica | October 9, 2021**

MORE INFO AND TO REGISTER:  
[HTTPS://HFSCSHAKASURF2021.EVENTBRITE.COM](https://hfscshakasurf2021.eventbrite.com)