

HEMOPHILIA ACTION

A PUBLICATION OF THE HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA

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2022 WORLD HEMOPHILIA DAY

Over 100 attendees joined HFSC for our World Hemophilia Day 2022 celebration in San Bernardino. This year's theme was "Access for All: Partnership. Policy. Progress."

Read the full article on page 5!



2022 FAMILY RETREAT

HFSC welcomed 35 families to Pali Retreat Center for our "Enchantment Under the Sea" themed retreat weekend.

Read the full article on page 6!

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2022 CALENDAR

**emPOWERment Webinar Series
(Virtual)**
October 12

**14th Unite for Bleeding Disorders Walk
LA Coliseum | Los Angeles, CA**
October 29

**HFSC Community Dinner
Costa Mesa, CA**
November 9

**emPOWERment Webinar Series
(Virtual)**
November 16

Snowflake Dinners
November & December
(To Be Announced)

HEMOPHILIACTION

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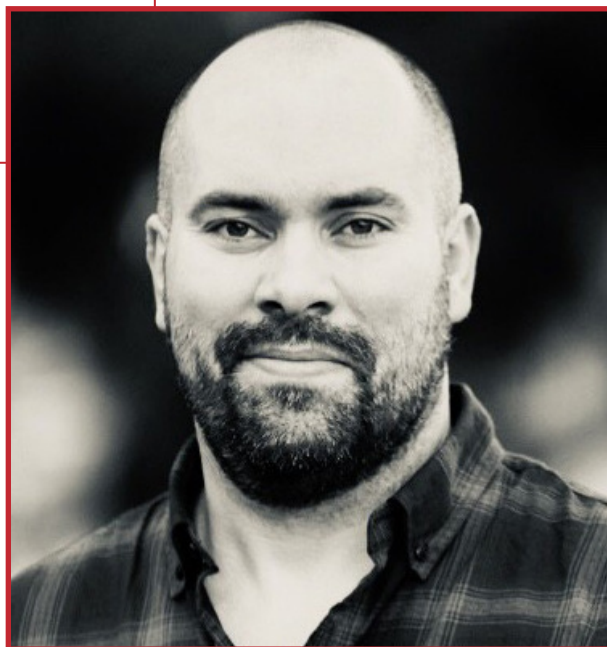
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A LETTER FROM THE BOARD PRESIDENT

I am delighted to welcome Rigo Garcia to the Hemophilia Foundation of Southern California as HFSC's new Executive Director, as of July 27, 2022. His background makes him the ideal person to see to the sustainability of the Foundation and strengthen its commitment to the rare bleeding disorders community in Southern California that is central to our 68-year history and mission.

He brings over 18 years of experience in health education, leadership, and outreach and a commitment to ensuring marginalized groups are provided primary care access. Most recently, Rigo was the Director of Health Education for the Venice Family Clinic, an organization that works to provide quality primary health care to people in need. We are excited to have found someone who will continue to successfully deliver on the organization's mission and who is looking forward to continuing our impactful work to ensure that those affected with rare bleeding disorders receive the support and resources they need.

During this time of transition, HFSC staff has been hard at work continuing to organize community events – it has been so invigorating seeing so many of you at these events, and I look forward to connecting with you at HFSC's upcoming programs for the remainder of the year. I am especially looking forward to our next big event, the 14th Annual Unite for Bleeding Disorders Halloween-themed walk, which will take place at the LA Coliseum on October 29. The walk is our largest fundraising event of the year, with funds raised supporting Camp Blood Brothers & Sisters, educational programs, emergency financial assistance, scholarships, and research.

Please visit www.uniteforbleedingdisorders.org/event/socal for more information on how to sign up, form a team and start fundraising! You can still participate and solicit donations from friends and family, even if you aren't able to attend the Walk in person. Not only is this a great opportunity to raise money for an important cause, but it is also a chance to meet other people from the bleeding disorders community.

I look forward to seeing you all again very soon! In the meantime, please feel free to reach out to me with any questions or if I can help in any way.

- Rick Kelly, MBA

Meet our new Executive Director on Page 4!

MEET OUR NEW EXECUTIVE DIRECTOR: RIGO GARCIA, MPH



Welcome to the bleeding disorder community. We would like to get to know you a bit more. Can you tell us a bit about your "backstory"? What led you to this particular career path?

Early in my career and before I started working in community health centers, I wanted to become a pediatrician. I held an internship at another community clinic as my first step on that path and ended up acting as the Spanish interpreter for a diabetes education class – almost by accident.

At first, I was just supposed to be the "Vanna White" of the class, showing patients models and how to use them. However, I soon realized that many of the patients were monolingual Spanish speakers. The Spanish-speaking patients would often turn to me for explanation. I knew that I needed to simplify information for these patients, and I started using metaphors and objects around the room to explain complex medical information and concepts that were difficult to translate directly. My intention was to make it easier for the patients to understand the information and make intelligent medical decisions for themselves and their families.

As soon as the class was over, the patients came up to me and thanked me. Then the nurse who ran the class told me I would be leading the class moving forward. Suddenly, I realized that I had a unique opportunity to translate complicated medical messaging in a simple understandable way

that patients could understand. That was the moment that my career path changed to the public health professional track.

This is a great story. So once you realized you wanted to work in public health, what was your next move?

I didn't know where to go but knew I wanted to help the community, my community. Since I had done the internship at a community clinic, I knew I wanted to work in the area of health. I worked in community health centers for over 18 years. I started my clinic career at Venice Family Clinic, working as a Clinic Coordinator. Initially I helped exit patients after they saw their clinician. This role was unique to Venice Family Clinic and taught me the workflow of a clinic while helping me understand the many roles many community clinics play as a one-stop health system for its patients, offering not only medical care but also dental care, substance use treatment, mental health services, vision screenings, child development services, health education and even street medicine for people experiencing homelessness. I have worked at three different community clinics in Southern California, all providing care in different geographical areas, but doing similar work.

Wow, community clinics do a lot for the community. But what led you to move into the bleeding disorders world?

Well, honestly, I did not have much experience coming into the bleeding disorder community, but had worked with a few patients who had hemophilia and also worked with patients who were HIV+ and had hemophilia. I knew that sometimes there was not enough program to provide support. When I saw that there was an opening to work with the Southern California region, I wanted to bring my strengths in program development to be able to continue the great work that has already been done but also explore new programs. Throughout my career I have always focused on patient and community programming. When I started as Director of Health Education at the Venice Family Clinic, I managed four staff members and two areas of focus. Nine years later, I was supervising 23 staff members and overseeing six areas of focus. As I continued along my career, my experience helped me to create programming that kept staff and patients in mind. That foundation allowed me to successfully create new programming.

So as the new Executive Director, what do you have planned?

The current office staff and Michelle Kim, previous Executive Director, have really established a very successful organization. HFSC has excellent programs and amazing community members. I want to be able to grow from what has been established. Be able to strengthen the programming we have and even expand on it. We have 9 counties we provide services to, and I want to make sure that all 9 counties have programming available to them. I also want to explore new programming, see where we can reach more of our community members and provide education and resources to them.

Anything else you want to tell your new community?

Yes, first off I want to thank the community for such a warm welcome, it truly means a lot to enter a new community but feel at home right away. Second, I want to make sure that everybody knows that I am here for my staff and my community members. I have worked creating and making sure programs are sustainable. I want to make sure that HFSC continues to meet the needs of our community members. I want the community to feel comfortable letting me know what is working great and what we can improve on. The only way we will all be successful is by working together. I am ready to roll up my sleeves and do what is necessary to make HFSC continue to be one of the leading organizations in the bleeding disorder community. I want to thank you for the opportunity and will make sure to do what I can to provide the best education, resources, and programming that we can. Thank you all and I will see you at our next event.



2022 WORLD HEMOPHILIA DAY

April 16, 2022

Over 100 attendees joined HFSC for our World Hemophilia Day 2022 celebration in San Bernardino. This year's theme was "Access for All: Partnership. Policy. Progress." with the hope of raising awareness and bringing hemophilia and other inherited bleeding disorders to the attention of policymakers who can increase sustainable and equitable access to care and treatment.

HFSC members gathered at New Delhi Banquet Hall for an Indian food buffet, wine and beer reception, HFSC goody bag and groundbreaking presentation from Dr. Akshat Jain, Pediatric Hematologist at Loma Linda Medical Center, on new therapies such as gene therapy and non-factor replacement. We were thrilled to hear testimonials from around the world including Dr. Mahoney from Ireland. Everyone looked fabulous in red!

#WHD2022 #WorldHemophiliaDay2022

2022 FAMILY RETREAT

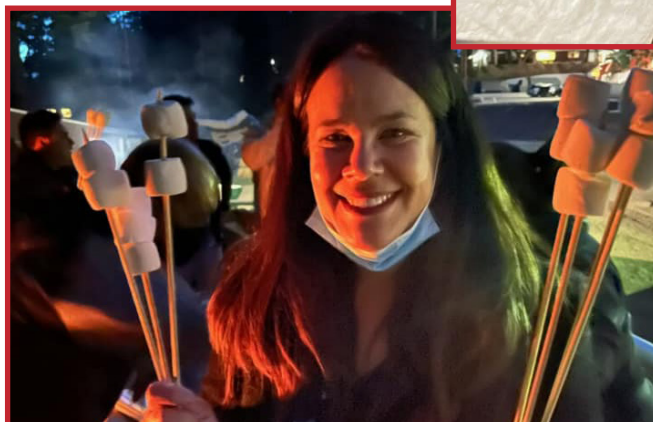
June 3-5, 2022

HFSC welcomed 35 families to Pali Retreat Center for our “Enchantment Under the Sea” themed retreat weekend. As families arrived on Friday evening, participants enjoyed sponsor booths, creating mermaid lanterns, and making Family Banners that were presented to the group after dinner. The first night finished off with a campfire complete with roasting marshmallows and making s’mores.

On Saturday morning, educational sessions were presented by Annabelle Garcia from Takeda, Dave Robinson, LMFT, of HFA, and Dr. Doris Quon of Orthopaedic Treatment Center. Kids and teens enjoyed games led by Jerry Garcia as well as laser tag and archery. In the afternoon, families were free to take part in activities such as swimming, wood shop and crafts, archery, ziplining, and the obstacle courses. The afternoon was rounded out with a wine and cheese reception followed by dinner and then the talent show, hosted by HFSC’s own Casey Shark O’Brien. Thank you to all who shared their awesome talents!

On Sunday after breakfast, families said their goodbyes and headed home. Thank you to our fabulous volunteers who made the weekend possible!

A special thank you to Platinum Sponsor, Takeda; Gold Sponsor, Genentech; and Booth Sponsors - Bayer, Octapharma, & Sanofi!





HFSC 2022 FAMILY INFO DAY

On April 30, HFSC members gathered in person at Ehler's Event Center in Buena Park for our annual Family Information Day. The event kicked off with "The Path to Resilience," where Rick Starks spoke about the benefits of tai chi in his life with his bleeding disorder. He led attendees in a relaxing tai chi routine to get everyone moving. Following this was the "Ages and Stages Panel," with community members sharing their personal bleeding disorders stories. Moderated by Dr. Nadia Ewing, HFSC Board Member, the panel consisted of Forrest Kelly, Heidi Jimenez, Erwin Luu, Maya Luna, Elizabeth Vargas, Victor Chavez and Oscar Horta.

During HFSC's Annual Awards, Sandy Knight was awarded Volunteer of the Year, and Medical Provider of the Year was awarded to Chris Chan. Haylee Slonaker and William Cerezo-Martinez were awarded Advocate of the Year awards; Fundraiser of the Year was awarded to Jesus and Paul Avila. Walk Co-Chairs Vicky Michua and Grace Hernandez spoke about the Unite for Bleeding Disorders Walk, encouraging everyone to create a team.

Teens enjoyed fun team building activities outside on the lawn with Jerry Garcia. The day ended with lunch and attendees receiving tickets to Knotts Berry Farm.

Thank you to all our volunteers! Thank you, Gold Sponsors: BioMarin, Novo Nordisk, Octapharma, Sanofi, Spark Therapeutics, and Takeda.

Thank you to our Gold Sponsors!



HFSC RESEARCH GRANT UPDATE

Last year, HFSC released two inaugural research grants to awardees: Center for Inherited Blood Disorders and Orthopaedic Treatment Center (OTC) for a total of \$60,000. OTC recently shared updates to their research via a poster presentation at the National Hemophilia Foundations Bleeding Disorders Conference in Houston in August 2022 and previously at the World Federation of Hemophilia conference.

The research, "Real Time Feedback on Joint Range of Motion," with: Authors James V. Luck, Jr. MD Orthopaedic Institute for Children, L.A. Orthopaedic HTC Doris Quon, MD, PhD Orthopaedic Institute for Children, L.A. Orthopaedic HTC, Cindy Bailey PT, DPT Orthopaedic Institute for Children, L.A. Orthopaedic HTC and Research Assistants : University of California Los Angeles, Abdullaraman Almalouie, MS-II Khalid Namooos MS-II and Arash Bakhian, Gaurrav Bhat, Technology and Software, seeks to address "real time" physical therapy modalities in hemophilic arthropathy which is associated with more severe arthrofibrosis than any other type of arthritis, especially of the knee and elbow.

The poster presentation is included below. HFSC is thrilled to make a direct contribution to improving the lives of those with rare inheritable bleeding disorders in Southern California.

Patient Controlled Biofeedback for Joint Range of Motion

SmartBug®



Project Aim: To develop a device that the patients can use to provide real-time feedback on joint ROM. This can increase patient motivation and improve both measurable and functional joint outcomes.

Introduction

Hemophilic arthropathy is associated with more severe arthrofibrosis than any other type of arthritis, especially of the knee and elbow. Even with removal of the arthrofibrosis at the time of reconstructive surgery, it often recurs resulting in loss of motion post operatively compared to patients with other types of arthropathy. Early, aggressive physical therapy is essential to preserve as much motion as possible. Some protocols require PT five days a week for the first two weeks and three times a week for the next one to two months. From a logistical standpoint this is impractical for many patients especially in the developing world. Currently there is no method for patients to monitor range of motion accurately at home.

Methodology & Materials

Electronic gyroscopes and accelerometers are currently in use in a variety of industries. Our group has adapted one such a device, TDK SmartBug®, to monitor joint ROM of the knee and elbow. This device interfaces with a PC computer with Windows 10. We also have developed a device using a similar chip that has a direct LCD readout for patients who are not computer literate.

Patients were trained by medical personnel to read and use the data, graphs and numerical information the SmartBug® and computer displays.



Results:

Accuracy of ROM was correlated with direct measurement using a goniometer by both the PT and surgeon as well as radiographic measurement. Variance was less than 5 degrees. The direct readout method was much simpler and required less patient instruction. The cost of each type of device was less than \$100.00 not including the cost of the computer. The patients were able to be trained in placement and use of the SmartBug® in conjunction with 2 office visits for medical follow-up or physical therapy. The first visit to train the patient on SmartBug® placement and computer interaction. The 2nd training visit is again in conjunction with a medical follow-up or physical therapy visit and the medical provider oversees the patient's placement and use of the device for correctness and full understanding. If needed reinstruction and corrections are done during this visit.

Conclusions:

Arthrofibrosis with significant loss of ROM is a major problem in patients with bleeding disorders. Patient monitored, accurate joint ROM can be a significant adjunct to rehabilitation of these patients following hemarthrosis and/or reconstructive surgery. Inexpensive, accurate devices were able to be presented to the patient for clinic and home use. Within 2 visits the patients were able to appropriately place and use the SmartBug® correctly.



Authors

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Gaurrav Bhat, Technology & Software, University of California Los Angeles

Acknowledgement

Thank you to the Hartley Family Foundation and the Hemophilia Foundation of Southern California for grant support.

ANNUAL REGION IX CONFERENCE

University of California San Francisco hosted the hybrid Region IX conference this year where the Western States Hemophilia Treatment Centers came together for 3 days to confer on best practices to serve the rare bleeding disorders community with particular emphasis on gene therapy as well as diversity, equity and inclusion (DEI).

HFSC was appreciative that staff had the opportunity to present as well – Michele Warner discussed gene therapy outreach within the SoCal community, and Cynthia Chavez shared about HFSC's ongoing DEI priorities. We are so thankful for our HTC's and their hard work and commitment to their patients!

Want to locate an HTC, but don't know how? Contact Cynthia Chavez, HFSC's Senior Outreach Manager, at 626-765-6656 or cynthia@hemosocal.org.



CHLA Team

emPOWERment WEBINAR SERIES

April 20, 2022

On April 20, HFSC hosted the third emPOWERment Webinar, "The Power of Empowerment," sponsored by Sanofi.

More than 60 families attended and learned about the importance of acknowledging strengths, embracing individuality, establishing and supporting partnerships. Attendees participated in a lively discussion all surrounding empowerment. Thank you to Sanofi for sponsoring this presentation.

June 28, 2022

Over 60 community members joined HFSC virtually on June 28 for our fourth webinar in our emPOWERment Webinar Series, "Estate Planning for People with Chronic Disorders."

Trust and Estate Planning can sound intimidating or complicated; however, parents of children with rare diseases should consider their importance. For example, if you die without a will in California, the care and destiny of your minor children will be out of your control and the decision will be left to the court. Speaker Steven P. Beltran, Senior Partner of Beltran Smith LLP, discussed the steps to take now to ensure your children are cared for in the event of your death.

Thank you, Mr. Beltran, for this informative and valuable presentation!

Thank you to our Sponsors!

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2022 HEMO HALLO-WALK!

14th Annual Unite for Bleeding Disorders Walk

Join us on Saturday, October 29, for our Halloween-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 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 most Spooktakular outfit for a chance to win a prize for best costume!

Questions? Please reach out to Michele Warner, Director of Development, at mwarner@hemosocal.org. Thank you for your support!



Register Today!



October 29, 2022
LA MEMORIAL COLISEUM

"SPOOKTACULAR" FUNDRAISING INCENTIVES



\$25

Earn your official 2022
Unite for Bleeding Disorders Event T-shirt!

Every walker who raises \$25 or more will receive the 2022 collectible shirt!



Unite Socks and
Shoelaces

\$250



HFSC Stainless Steel Bottle and
Stadium Blanket**

\$500

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



Beach Towel

\$1,000



Jacket & VIP tent***

\$2,500

*** 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.

HFSC COMMUNITY DINNERS



Lancaster Community Dinner
06.07.22

HFSC hosted a wonderful community dinner in Palmdale with all in attendance enjoying amazing Italian food at Gino's Italian Ristorante while learning the importance of bonding with blood brothers and sisters! Thank you, Sanofi, and Albert Maffei, for your generous support and all who joined us. It was wonderful to see everyone! Thank you to our community liaison, Julie Slonaker, for helping organize this event!



Los Angeles Community Dinner
06.14.22

With over 50 community members in attendance, HFSC hosted a dinner at Tamayo's Restaurant in the Los Angeles area with attendees learning about how to help young adults transition towards independence. Thank you, Bayer team for an informative presentation and for your incredible support of HFSC!

HFSC COMMUNITY DINNERS *(continued)*



Santa Barbara Community Dinner
05.11.22

We had a wonderful gathering in Santa Barbara on May 11 at Harry's Plaza Café with our bleeding disorders family. All in attendance received tips and shared about handling anxiety and stress. Thank you Dr. Quon and our community dinner sponsor, Novo Nordisk, for your amazing support!



Whittier Community Dinner
05.25.22

¡El grupo Mujeres Enlazadas se reunió para aprender sobre terapia génica! ¡Fue una noche muy informativa donde las mamás, pacientes y cuidadores pudieron hacer varias preguntas sobre esta nueva terapia! ¡Gracias a Spark Therapeutic y Guillermo Campillo por su apoyo incondicional a nuestra comunidad!



2022 PARKER INVITATIONAL

A heartfelt thank you to Perry Parker for hosting the Parker Invitational, a golf tournament in Pebble Beach, raising nearly \$12,000 for HFSC!

The event took place from May 30 – June 2, 2022, and included a full field of senior golf professionals from around the globe and their 3-person 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 29 - June 1, 2023. If anyone is interested in playing or volunteering, Perry can be reached at perryparkergolf@gmail.com.





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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
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- 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

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Institute for Children
Hemophilia Treatment Center

IN ALLIANCE WITH  UCLA Health

ortho-institute.org/hemophilia

SHAKA SURF FEST

Over 100 participants joined us on June 25 at Santa Monica Beach for Shaka Surf Fest 2022 riding radical waves and wiping out with style. The weather was perfect and the company even better.

Thank you to the amazing surf lesson company, Aqua Surf School, and to our sponsors: Bayer, CSL Behring, Novo Nordisk, Octapharma, Sanofi, and Takeda. Thank you to Brothers Healthcare, our lunch sponsor, CVS for the lip balm and sunblock, and to Guided Alliance for snacks! We love and appreciate all our volunteers, especially Dr. Doris Quon, who attentively watched over all the surfers the entire time!





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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, 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!

The poster features a purple background with various Halloween-themed illustrations: a white ghost, a black bat, a witch's hat on a pumpkin, a black cat wearing a striped witch hat, and several colorful candies. The text is centered and reads:

HEMO Hallo-Walk
HFSC'S UNITE FOR BLEEDING DISORDERS WALK
October 29, 2022 • 9 am-1 pm
LA MEMORIAL COLISEUM
Come Dressed In Your Most Spooktacular Costume!
Register today for our largest fundraiser of the year, in support of advocacy and access to care, educational and support programs, research, and Camp Blood Brothers & Sisters!
[UNITEFORBLEEDINGDISORDERS.ORG/EVENT/SOCAL](https://uniteforbleedingdisorders.org/event/socal)

Hemophilia Foundation of Southern California

Unite
for Bleeding Disorders