

# HEMOPHILIA ACTION

A PUBLICATION OF THE HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA

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## SEPTIEMBRE 17-19, 2021 FAMILIA DE SANGRE 2021

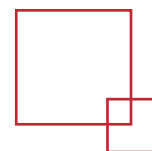
La Fundación de Hemofilia del Sur de California, la Fundación de Hemofilia del Norte de California, la Fundación de Hemofilia del centro de California y la Asociación de Hemofilia Condiciones del Condado de San Diego con nuestros invitados de la Asociación Puertorriqueña de Hemofilia y de Sangrado fueron anfitriones de la Quinta Conferencia Anual Familia de Sangre recientemente. Aunque se llevó a cabo de nuevo virtualmente, ¡más de 300 familias se unieron a nosotros para un fin de semana de educación, empoderamiento y apoyo!

La conferencia comenzó el viernes por la noche con la sala de exposiciones con visitas en vivo a través de Zoom, una sesión de apertura moderada por el ex miembro de la Junta de la NHF, Jorge de la Riva, y bienvenida por parte de los patrocinadores. Luego, los asistentes eligieron entre un excelente concierto del Mariachi Arcoiris de Los Ángeles y una noche de juegos familiares con el DJ Kevin, donde las familias tocaron algunas canciones emocionantes con premios.

El sábado comenzó con sesiones muy informativas y con una gran asistencia que incluyeron Inmigración, Terapia génica, Trastornos hemorrágicos ultrararos y actualizaciones de Covid-19, entre muchos otros. Se compartieron historias personales y se derramaron lágrimas durante el panel "Culpa Intachable" para las madres mientras se conectaban con otras mujeres de la comunidad, moderado por Erika Bocanegra, Trabajadora Social Clínica. El domingo, los participantes pudieron escuchar varias sesiones educativas adicionales, incluida la salud de las articulaciones, y vieron una presentación de diapositivas conmovedora basada en el emocionante juego de GooseChase Scavenger Hunt. *(Article continued on page 10)*

## NHF BLEEDING DISORDERS CONFERENCE 2021

HFSC was a proud recipient of two awards at this year's conference! Read the full article on page 10.



# 2022 CALENDAR

## Industry Forum: Pipeline Products (Virtual)

January 19

## Industry Forum (In-person)

January 22

## Community Dinner: Bakersfield (In-person)

January 26

## emPOWERment Webinar Series (Virtual)

February 9

## emPOWERment Webinar Series (Virtual)

March 2

## Women's Retreat (In-person)

March 19 - 20

## World Hemophilia Day (Location TBD)

April 16

## emPOWERment Webinar Series (Virtual)

April 20

## Family Information Day (In-person)

April 30

## Family Retreat Weekend (In-person)

June 3 - 5

## Camp Blood Brothers and Sisters (In-person)

July 19 - 23

# HEMOPHILIACTION

is published quarterly by

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of Southern California

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## A LETTER FROM THE BOARD PRESIDENT

With continued strides made in the fight against COVID-19, we were able to host several in person events recently, including community dinners and our 13th Annual Unite for Bleeding Disorders Walk: Let the Games Begin, where more than 300 attendees came out to the LA Coliseum, in support of those with bleeding disorders in Southern California. It was amazing to see everyone, many of you for the first time in almost 2 years!

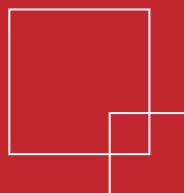
Though much progress has been made against the virus, the health, well-being, and safety of our community remains a top priority for HFSC. To that end, the Board recently approved policy guidelines, based on guidance from public health experts, that will continue to allow us to meet. For all upcoming events, all attendees ages 12 and older need to present proof of COVID-19 vaccination or a negative COVID-19 test result within 72 hours prior to entry. In addition, all attendees must continue to wear masks at all times, regardless of vaccination status, unless eating or drinking. These guidelines also comport with the National Hemophilia Foundation (NHF) recommendations and ensure the safety of all.

A heartfelt thank you to all of you for continuing to help keep our community safe and healthy during these unprecedented times. Please feel free to reach out to me with any questions or if I can help. In the meantime, stay healthy and safe. - Rick Kelly, MBA

## A LETTER FROM THE EXECUTIVE DIRECTOR

I am not sure how 2021 whizzed by so quickly! While I am still working from my daughter's child size desk at home and attending meetings daily on Zoom, I look forward to the day when we can safely be together in person. We hope to do so in 2022. In the meantime, I am so thankful to many of you for continuing to stay connected and being a part of our extremely special HFSC community, even during the second year of the pandemic. You are the reason we continue to advocate, educate, and empower people with rare bleeding disorders in California. I was particularly overwhelmed with emotion that despite all our challenges, you generously donated a record amount during our 13th Annual Unite Walk and I couldn't be more humbled to lead such an impactful organization. Wishing you all a fantastic 2022 filled with hope, love, and peace. As always, please reach out to me with any questions, concerns, or ideas! Warmly, Michelle

- Michelle Kim, Esq.



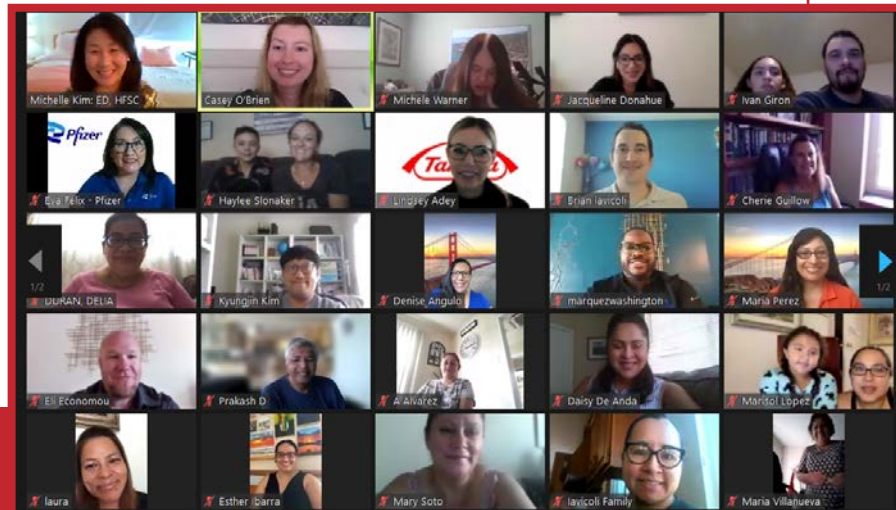
# WHAT'S NEXT? YOU DECIDE.



At Genentech, we're committed to creating programs for you, with you. From a web series focused on finding the *magic* in life, to a tournament for gamers, to workshops designed to help you think well, do well, and be well, we're here to help you take on what comes next.

VISIT [GENENTECHHEMOPHILIA.COM](https://www.genentechhemophilia.com)  
TO SEE HOW WE'RE CREATING  
WHAT'S NEXT, TOGETHER.





## BACK TO SCHOOL

On August 7, 2021, HFSC hosted the virtual 7th Annual Back to School Symposium. Participants received education on student rights in school and advice from a panel of school experts on challenges that parents and students may face, and ways to achieve success in school while managing their bleeding disorder. Participants also received access to resources in English and Spanish, which can also be accessed at this link: <https://conta.cc/3xIW7Ds>.

Thank you to our many speakers including Dr. Juliana Bloom, Eli Economou, Esq., Brian Iavicoli, RN, Dr. Doris Quon, and Dr. Jackie Donahue for our English sessions, and Martha Boria-Abreu, Josefina Salas, Erika Margarita Bocanegra, MSW, Al Vega, Denise Angulo, MSW, and moderator Karla Reynado Arce for our Spanish sessions. The symposium was incredibly informative and impactful because of these amazing speakers.

Thank you to support from HFA and the Hemophilia Alliance Foundation, and from our generous sponsors: Genentech, Novo Nordisk, Pfizer & Takeda!



## Septiembre 17-19, 2021 Familia de Sangre 2021 *(continued from cover)*

Este año, FDS se complace en dar la bienvenida a miembros de la comunidad de habla hispana de 15 estados y Puerto Rico. Estamos muy agradecidos con todos los que asistieron e hicieron de la conferencia virtual de este año un gran éxito y esperamos conectarnos con ustedes en persona o virtualmente para la Familia de Sangre 2022 del próximo año. Gracias a la Federación de Hemofilia de América por su asociación. Muchas felicidades a los ganadores del Goosechase: Equipo Bella GT Crew, Equipo L.E.M., Familia Martin Gtz., Familia Fraden, Familia Camacho, Familia Ordaz, Familia Gurdian, Familia Brolezi, Familia Cardenas, Familia Vizuetto, Karla Obeso, Socorro Cerezo, Coryene Reyes y Mia Castaneda.

Gracias a todos nuestros voluntarios, Jorge de la Riva, Karla y Mauricio Reinado, Rosie Villalpando, Mathew Casas, Victor Chavez, Maya Luna, Sonia Ruiz, Karla Obeso, Wayne Guzman, Shin Chen, Salvador Marquez, Jessica Jimenez, Omar Fazalet, Mia Castañeda, Keely King, Vicky Michua, Aileen O'Brien, Linda y Paul Clement. ¡Sin su ayuda y apoyo esta conferencia no sería posible!

También estamos agradecidos con el patrocinador de titanio Takeda y sus presentadores del equipo educativo de habla hispana: Annabelle García, Susana Escojido, RN, Maria Raquel Tovar y Patricia Espinoza-Thompson.

## NATIONAL HEMOPHILIA FOUNDATION BLEEDING DISORDERS CONFERENCE 2021



NHF hosted its 73rd annual virtual conference last August presenting a wealth of educational information. HFSC was a proud recipient of two awards at the conference: the 2020 Walk Chapter of the Year Award and the Ziggy Douglas Memorial Innovation in Teen Programming Award. This award was given for our dynamic work with the teens in California. Other local recipients included Dr. Cindy Bailey, Physical Therapist at Orthopaedic Hemophilia Treatment Center, for receiving the PT of the Year Award. The Ryan White Youth Award went to Nathan Mermilliod for his advocacy work.



HFSC is also proud of our local teens who won a Teen Impact Award for their various achievements: Mathew Casas, Bailey Martinez, Naomi Giron, Luke Kim, Haylee Slonaker, Vijaya Prathigudupu, and Ashritha Prathigudupu.

We are so proud of everyone! NHF is hosting the 2022 BDC conference from August 25-28, 2022 in Dallas, Texas.





## Gracias a nuestros Patrocinadores

Patrocinador de Titanio



Patrocinadores de Platino



Patrocinadores de Oro



# HFSC PRESENTS CANNABINOID USE FOR PAIN AND ANXIETY

09.30.2021

HFSC hosted a deeply informative presentation with Dr. Sherry Yafai from The RELEAF Institute, who presented very impressive and interesting information on Cannabinoid Use for Pain and Anxiety, going overtime by 30 minutes! Thank you also to Dr. Doris Quon, Medical Director of OTHC, for responding to questions relating to bleeding disorders. If you missed the session, it is available on the HFSC YouTube channel (along with many other educational and entertaining videos). Please follow us!

<https://youtu.be/RPx2wkFtbqk>

# HFSC ADVOCACY UPDATE

Governor Newsom recently signed 770 new laws in California, and HFSC is thrilled that 3 bills we supported made it through.

A special thanks to Senator Anthony Portantino for supporting student mental health and the critical step therapy bill, which was supported by an amazing coalition of other organizations including the Hemophilia Council of CA, National Hemophilia Foundation, and Hemophilia Federation of America.

*We're Listening*



At Pfizer Hemophilia, we have always been deeply committed to listening to what you have to say. Our programs and resources are all designed in response to the needs of the hemophilia community.

**We are grateful for having the chance to partner with you.**

—Your Pfizer Hemophilia Team

 Hemophilia Foundation  
of Southern California

## INTRODUCING THE EMPOWERMENT WEBINAR SERIES

Join HFSC once a month for a series of webinars focusing on empowerment and advocacy. All webinars will be held on Zoom.

### UPCOMING WEBINARS:

FEBRUARY 9: ADVOCACY PANEL

MARCH 2

APRIL 20

JUNE 15



More information and registration links coming soon!



# CAMP AT HOME: WE ARE FAMILY

HFSC and 42 years of Camp! Though it was virtual, we still were able to connect and experience the magic of Camp with The Painted Turtle from July 23 - 25! Families cut loose and enjoyed their favorite camp activities including making their own campfire, marshmallow toasting, Stage Day, the Pinewood Derby, and, of course, no-hands spaghetti!

We are astronomically thankful to our sponsors who joined our camp visitor's day!

Camp Blood Brothers and Sisters will be held July 19 - 23, 2022 at the Painted Turtle.



## Thank You To Our Sponsors

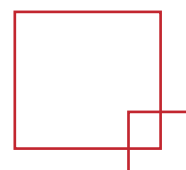
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# COMMUNITY DINNER SPONSORED BY NOVO NORDISK



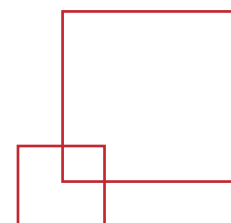
08.18.2021

An amazing presentation where those in attendance were able to learn how small changes can improve the overall health of people with bleeding disorders!

Ms. Cathy Tiggs did a remarkable job providing healthy and useful tips!

Thank you, Novo Nordisk, for your support!

# COMMUNITY DINNER SPONSORED BY PFIZER

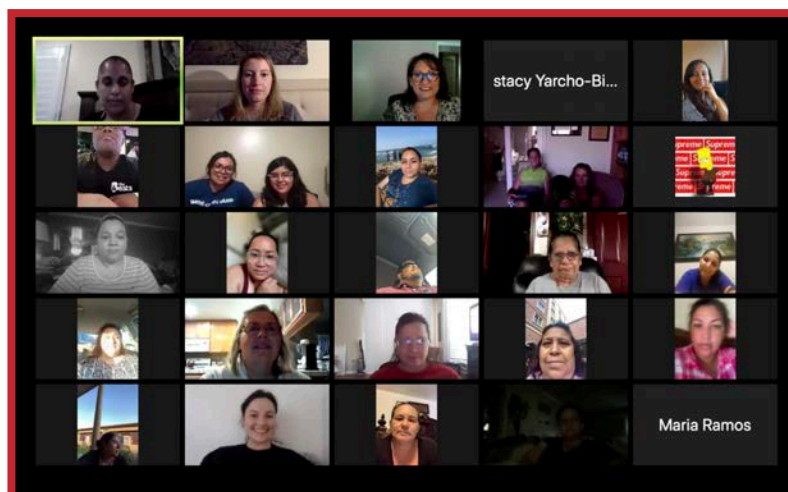


07.14.2021

HFSC community members had the pleasure to hear from Eva Felix!

Eva provided tips on working out and staying active during the summer heat. It's so wonderful seeing everyone!

Thank you, Pfizer, for your sponsorship!



# NHF MASAC MEDICAL ARTICLE

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With emergency evacuations and natural disasters such as earthquakes and mudslides, HFSC feels that it is important to remind all our families about the importance of keeping extra doses of medication on hand for emergencies. Please review this recommendation from the National Hemophilia Foundation (NHF):

*The following recommendation was approved by the Medical and Scientific Advisory Council (MASAC) on April 13, 2014, and adopted by the NHF Board of Directors on June 5, 2014.*

## **Background**

Patients with hemophilia and other bleeding disorders require immediate availability of factor concentrate in the event of an emergency. All patients with hemophilia, regardless of whether they are on home treatment or not, need an emergency supply of factor for self-infusion or to take to the nearest emergency department or medical facility. Unfortunately, insurance companies and Medicaid are limiting the amount of factor a patient can have at home or denying refills until patients are down to the last 2 doses. This practice places the patient at risk for severe and continued bleeding in the event of an emergency because it does not provide families with enough factor to cover a serious bleed over a long weekend or when a natural disaster makes it impossible for factor deliveries to occur in a timely manner.

Hurricane Katrina provides an example of the difficulties encountered in a natural disaster. The accompanying document entitled "Background Information" details the responses of CDC and NHF to this disaster and their successful efforts to provide medical information and factor for patients displaced by the hurricane.

In Utah, California and other states, there is a concern about the effect of a major earthquake. The "Background Information" provides some thoughts on this issue. The "Background Information" also delineates the difficulties with Medicaid that are being encountered in Michigan.

## **MASAC Recommendation:**

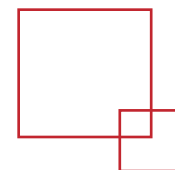
All patients with severe and moderately severe inherited bleeding disorders for whom clotting factor concentrates (CFC) are available should have 7 extra doses (special consideration of number of doses for inhibitor patients) of the CFC at home to be available in the event of an emergency. The dose should be based on the factor level to achieve a hemostatic level of 100%, rounded up to the nearest vial size. The dose and frequency should be determined by the patient's health-care provider.

**Individuals should consult the FDA Emergency Preparedness website for additional information on emergency preparedness.**

*This material is provided for your general information only. NHF does not give medical advice or engage in the practice of medicine. NHF under no circumstances recommends particular treatment for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.*



# SEEK IMMEDIATE MEDICAL CARE FOR THESE BLEEDS



**Here's everything you need to know about the most dangerous bleeds, including symptoms and preventive measures.**

*by Michael Hickey*

Members of the bleeding disorders community regularly deal with small bleeds and, most of the time, they have a number of ways to handle them on their own. But some bleeds require immediate medical attention, depending on their severity and location. Knowing the difference between a regular bleed and a severe one could be the difference between life and death. After all, the No. 1 cause of preventable death from trauma is uncontrolled bleeding.

Here's what you need to know about detecting and preventing these dangerous bleeds.

## **Symptoms of Dangerous Bleeds**

For people with hemophilia, there are five major sites of serious bleeding that can threaten your life or cause long-term damage:

- Intracranial (head) bleeding
- Ocular (eye) bleeding
- Neck or throat bleeding
- Abdominal bleeding
- Kidney or bladder bleeding

These bleeds require a call to your healthcare provider, immediate intervention, or a trip to the emergency room. Additionally, factor levels should be raised based on your medical team's recommended treatment.

## **Head Bleeding**

Bleeding in the brain can happen after a head injury or for other unknown reasons. Observable symptoms include prolonged headaches, vomiting, dizziness, confusion, slurred speech, sensitivity to bright lights, dilated pupils and seizures.

## **Eye Bleeding**

Often the result of an injury, eye bleeds cause the white of the eye to become reddish and cause double or blurred vision. They can also cause pain when you move your eyes. If you experience these symptoms, seek medical care. In the meantime, hold an ice pack on the eye to slow the bleeding and reduce swelling.

## **Throat Bleeding**

Bleeding from the mouth can be minor—for example, when you bite your tongue or cheek—but it can also be serious, as it can cause swelling that can impair breathing. Symptoms of serious throat bleeds include swelling or discoloration in the neck, trouble swallowing or breathing, choking, coughing or throwing up blood, and change in your tone of voice.

## **Abdominal Bleeding**

Bleeding in the stomach or intestines can be serious. You may have a bleed in your gastrointestinal tract if you're experiencing weakness, paleness, bloody or black stool, vomiting or coughing up blood, abdominal pain, or a distended, firm abdomen.

## **Kidney or Bladder Bleeding**

Urinary tract bleeds result in blood in the urine, which can come from multiple places along the urinary tract, such as the ureters, bladder, and urethra. Look for these symptoms:

- Pink urine, which may be a sign of an early urinary tract bleed
- Bright red or brown urine, which may be a sign of a later, more serious bleed
- Lower back pain
- Frequent urination
- Pain when urinating

Call your hemophilia treatment center for guidance on dealing with a urinary tract bleed, as proper treatment depends on the source of the bleeding.

## **Stay Safe While Staying Active**

Dangerous bleeds are often the result of a traumatic injury, such as a sports injury or bicycling accident. While it's important to remain active, there are ways to do so safely to lower your risk of severe injury.

You can avoid high contact sports such as football, boxing, wrestling or hockey, and instead opt for more low-impact activities, including cycling, walking, jogging, yoga and swimming. Even during low-impact exercises, be sure to wear the appropriate safety equipment—a helmet when riding a bike, for example.



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



"Hold 'Er Wide!" Jake Dunham would say.

Living life with maximum speed and effort was his mission despite facing challenges from severe hemophilia. On this third anniversary of the massacre at the Borderline Bar and Grill in Thousand Oaks, we remember you Jake, the fearless. Your spirit and strength live on in many of our youth. In these troubled times may we all remember and shout out, "HOLD 'ER WIDE!"

Love is stronger than hate. Jake, you are missed.



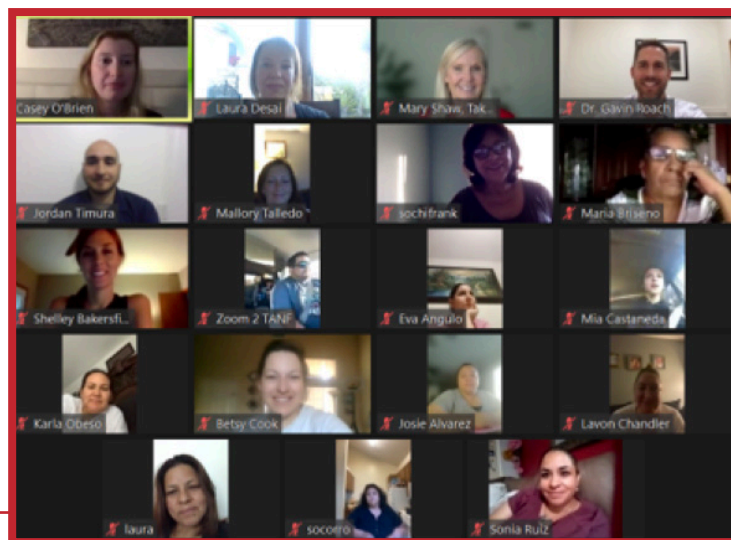
# COMMUNITY DINNER SPONSORED BY TAKEDA

07.28.2021

HFSC hosted an engaging virtual community dinner and over 50 households participated for the presentation, "Do What Moves You, Staying Active," sponsored by Takeda.

Those in attendance learned about safe physical activities that can be incorporated into our daily routines! Thank you to Dr. Gavin Roach for your wonderful presentation and discussion.

Thank you to our sponsor, Takeda, for your support!



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LET'S GO

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about the study.



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about PK at [UnderstandingPK.com](https://UnderstandingPK.com)

PK; Pharmacokinetics

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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)!

**Hemophilia Foundation of Southern California**

# 2022 HFSC WOMEN'S RETREAT

Join us in person for an overnight retreat of support, self-empowerment, education and fun!

**Saturday, March 19 - Sunday, March 20, 2022**

Marriott Irvine Spectrum  
7905 Irvine Center Drive  
Irvine, CA

Begins Saturday 11:00am | Ends Sunday 11:00am

<https://hfscwomensretreat2022.eventbrite.com>

**Hemophilia Foundation of Southern California**

## HTC TOWNHALL: PIPELINE PRODUCTS

January 19, 2022 | 7:00-8:30pm  
Zoom

Moderator: Dr. Nadia Ewing  
Panelists: Dr. Soni, Dr. Quon, Dr. Young  
\$20 Amazon Gift Card per Household  
Register: <https://bit.ly/3GOD2po>

## 6TH ANNUAL INDUSTRY FORUM

January 22, 2022 | 9:00am-1:30pm  
Pasadena City College

Join HFSC and learn about new and existing products to treat Hemophilia A, B and vWD.  
Attendees ages 3+ will receive a Six Flags ticket.

Register:  
<https://hfscindustryforum2022.eventbrite.com>

Consistent with PCC rules, Covid Vaccination required.