

HEMOPHILIA ACTION

A PUBLICATION OF THE HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA
VOLUME 14 | ISSUE 4 | FALL | 2018

FAMILIA DE SANGRE SEPTEMBER 7-9, 2018

HEMOPHILIA MEMORIAL AT THE NATIONAL AIDS MEMORIAL GROVE



El 7-9 de septiembre de 2018 la 2ª Conferencia anual de Familia de Sangre fue organizada en Oakland, California por la Fundación de Hemofilia del sur de California, la Fundación de Hemofilia del norte de California, la Fundación de Hemofilia central, y La Asociación de Hemofilia del Condado de San Diego, el segundo año de esta Conferencia de habla hispana acogió a más de 450 asistentes.

La Conferencia comenzó el viernes por la noche con una recepción de bienvenida y comentarios del abogado y ex Presidente de la Mesa Directiva de NHF, Jorge de la Riva. ¡La cena se celebró en la sala de exposiciones, seguida de una bendición especial de los danzantes aztecas, Calpulli Tonalehqueh y bailando con el DJ J. Martin Reyes!

El sábado comenzó con una sesión inaugural con comentarios de bienvenida del Sr. de la Riva seguida de diferentes sesiones incluyendo "Entendiendo la Enfermedad de von Willebrand", "Fuerza Interior de Pacientes y Cuidadores", "Entendiendo los Inhibidores: factores de riesgo y tratamiento", "Estableciendo Expectativas Educativas", "Hablando de su Hemofilia-hombres latinos, "y para los adolescentes," Sesión para adolescentes: el Desafío Juvenil".

La segunda parte de sesiones incluyó "Resiliencia: Creciendo a Través de los Desafíos de la vida", "Cómo Prepararse para Cambiar las Leyes y Políticas de Inmigración", "Consejos para Mejorar la Comunicación con los Proveedores de Atención Médica", "Prepararse para lo que sigue", "El Dolor es Importante" y "Getting in the Game" para los adolescentes. La última ronda de sesiones para el día fueron "El Poder de la Personalización-MYPKFIT," "Tecnología de Ultrasonido," "Hermanas de HFA", "Límites y Defensa y Defensa del Estado de HCC," y "Fear Factor" en la sesión para adolescentes.

ARTÍCULO CONTINÚA EN LA PÁGINA 1



2019

CALENDAR OF EVENTS

February 13 **Mujeres Enlazadas por Sangre Dinner**

Castaway - San Bernardino |
San Bernardino, CA

February 23 **SoCal EmPOWERment Forum
& 4th Annual Bloody Hot Salsa
Challenge**
Pickwick Gardens | Burbank, CA

March 22-23 **Women's Retreat**
Crowne Plaza Ventura Beach |
Ventura, CA

March 27-29 **Washington Days (NHF)**
Washington, DC

April 4-7 **HFA Symposium – HFSC is
Local Host Member Org**
San Diego, CA

April 28 **Blood Brotherhood/Dads in
Action – One Day Retreat**
Orange, CA

May 10 **Family Information Day Kickoff
Dinner – Women's Educational
and Small Group Forum**
Knott's Berry Farm Hotel |
Buena Park, CA

May 11 **Family Information Day**
Knott's Berry Farm Hotel |
Buena Park, CA

May 13-15 **Future Leaders and Legislative
Days (HCC)**
Sacramento, CA

June 7-9 **Family Retreat**
Pali Retreat Center |
Running Springs, CA

THANK YOU, DONORS

IN MEMORY

William and Judy Metscher in memory of Richard Katz
Amy Field in memory of Jake Dunham
Anonymous in memory of Jake Dunham

IN HONOR

W.M. Keck Foundation in honor of Thomas Rieker and Sunny
Rieker Pierce
Ellen Greenberg in honor of Dr. Richard Metz

MARK P. LEONE CAMP FUND

Keith Lehmann and Catherine M. Leone

GERRY GREEN MEMORIAL FUND

Deborah Sazdoff

GENERAL DONATIONS

Bayer
Colburn-Keenan Foundation
Donna Gallegos
Jeffrey and Mary Lou Wright
Kroger
M. Iwanaga
Martha Guevara
Steve Lowe

BOARD OF DIRECTORS

Sandy Davis, President
Sandy Knight, Treasurer
Carol Jung, Secretary

Shin Chen, Silvia Garcia, Wayne Guzman, Rick Kelly, Kelvin Lee,
Devon Rios, Pedro Sanchez, MD, Ron Staaek, Michele Warner

Doris Quon, MD, Medical Advisor

HFSC TEAM

Michelle Kim, Executive Director
Laura Desai, Operations Manager
Cynthia N. Chavez, Outreach Manager
Susan Hall-Hardwick, Accounting
Casey O'Brien, Event Coordinator

DISCLAIMERS:

The Hemophilia Foundation of Southern California (HFSC) does not endorse any particular pharmaceutical manufacturer or home care company.

PLEASE NOTE: The companies whose advertisements are listed herein have purchased this space, and are NEVER provided with member's names, addresses or any other personal details. Paid advertisements should not be interpreted as a recommendation from HFSC, nor do we accept responsibility for the accuracy of any claims made by paid advertisements. Since we do not engage in the practice of medicine, we always recommend that you consult a physician before pursuing opinions expressed in this publication are not necessarily those of the HFSC, or of its editorial staff.

Material printed in this publication may be reprinted with express prior written permission from the Executive Director.

HEMOPHILIA ACTION

is a published quarterly by

The Hemophilia Foundation of Southern California

► SANGRE ARTÍCULO CONTINUADO...

El sábado por la noche, los asistentes hicieron su camino hacia el círculo conmemorativo de la hemofilia en la arboleda nacional del Memorial del SIDA en San Francisco quienes muchos lo experimentaron por primera vez. El Director Ejecutivo, John Cunningham, compartió acerca de la importancia y la historia del Memorial. El miembro de la comunidad y el representante del Consejo de hemofilia del HFSC, Oscar Horta, habló sobre las dificultades de su niñez en un discurso conmemorativo que llevó a todos a llorar.

A continuación a los asistentes hicieron su camino, cruzando la calle, a la Academia de Ciencias de California donde gozaron de acceso privado al acuario y diversión educativa en diferentes estaciones patrocinado por Bioverativ, CSL Behring, y Shire. ¡Muchas gracias a la Dra. Quon y Chris Chan del centro de tratamiento ortopédico que sirvieron como nuestro equipo médico y a los muchos voluntarios que ayudaron a hacer que este evento sucediera! ¡Un agradecimiento especial a Linda Clement y Vohn Dum Dumaya por sus habilidades de fotografía! ¡Un agradecimiento especial para la Coordinadora de HFSC, Cynthia Chavez por su arduo trabajo! Gracias también a la Federación de Hemofilia de América y la Fundación Nacional de Hemofilia por su apoyo de haber tenido presentadores excelentes.

El domingo por la mañana, los asistentes se reunieron una última vez para un desayuno con una presentación innovadora de Shire, llamado "El Viaje del Factor" antes de partir.

Gracias a nuestro patrocinador diamante: Shire; a nuestros patrocinadores platinos: Bioverativ, CSL Behring y Novo Nordisk; a nuestros patrocinadores de oro: Bayer y Genentech; a nuestros patrocinadores de plata: Brothers Healthcare, Fidelis Specialty Pharmacy y Octapharma. ¡Gracias a nuestros presentadores y voluntarios increíbles!



GRACIAS A NUESTRO PATROCINADOR PLATINO:



GRACIAS A NUESTROS PATROCINADORES PLATINOS:



PATROCINADORES DE ORO:



Guardar la fecha de FDS 2019!
Septiembre 6-8, 2019 Anaheim, CA.



A LETTER FROM THE BOARD PRESIDENT

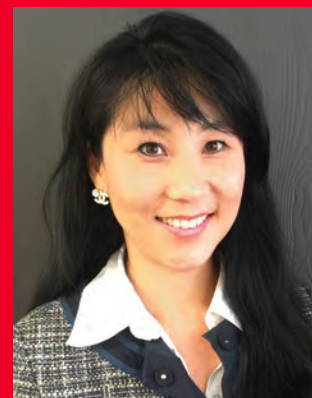
HFSC experienced a magical year this past 2018 hosting 26 events for the bleeding disorders community! I am so thankful for all the volunteers, staff and talented Board of Directors for making these impactful and remarkable events possible. Moreover, I want to thank all of you who participated in and donated to our 2018 Unite for Bleeding Disorders Walk. You helped raise almost \$124,000, double the amount from last year! For this achievement the Hemophilia Foundation of Southern California won the "Walk Chapter of the Year" from NHF! Thank you and Happy New Year from my home to yours.

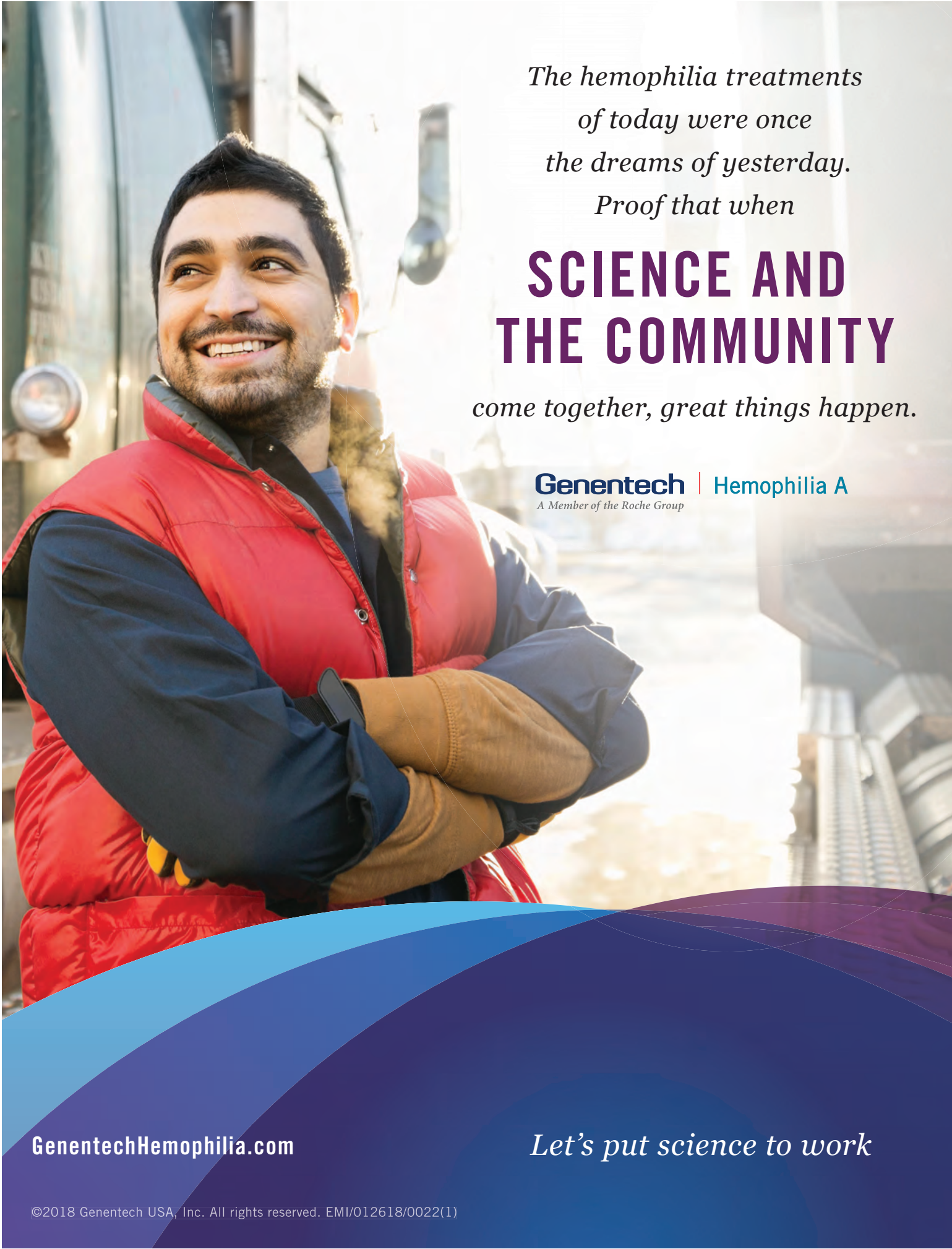
Sandy Davis, HFSC Board President

A LETTER FROM THE EXECUTIVE DIRECTOR

I can't believe another year has gone by so quickly. We hope HFSC has been a blessing to you and your family and that we have made a positive impact on your lives as you live with your bleeding disorder. As we look to 2019, we hope to do even more to support you and as always, please reach out to me or anyone in the office if you need assistance. Moreover, you have all been a blessing to us as we laughed and cried through life's struggles. It is an honor to serve the community. I wish you all a blessed holiday season full of health, love and good cheer!

Michelle Kim





*The hemophilia treatments
of today were once
the dreams of yesterday.*

Proof that when

SCIENCE AND THE COMMUNITY

come together, great things happen.

Genentech | Hemophilia A
A Member of the Roche Group

GenentechHemophilia.com

Let's put science to work



IN MEMORIAM: JACOB KENNETH DUNHAM

NEWBURY PARK, CA

On November 7th, 2018, the bleeding disorders community was in deep sorrow over the loss of a young blood brother. Jake Dunham's life was stolen in the horrific Borderline shooting in Thousand Oaks, CA. Jake was only 21 years old and was born on June 12th, 1997.

Jake lived an unimaginable legacy of hardship and perseverance. Jake struggled with school and the inability to focus in a classroom setting until he reached high school where an amazing teacher by the name of Mr. Rosebaugh worked with him after school everyday to help him graduate. He also grew up with a rare bleeding disorder called hemophilia and lost the vision in his right eye at seven years old due to a severe injury.

Despite his blood's inability to clot efficiently and being blind in one eye, Jake still took on extreme sports such as BMX riding, dirt bike riding, off-roading, wake surfing and kneeboarding.

It wasn't uncommon for Jake to come home after a day of hanging out with his friends with road rash, internal bleeding and broken bones (including a skull fracture) yet nothing stopped him from doing the things he loved. To Jake's friends he was the life of the party. He was fearless and creative and lived life larger than most people could dare to imagine.

You could find him and his friends in his parent's garage building contraptions on any given day, such as a gas powered go-kart with 12 inch pipe covering the back wheels so they could drift it around the neighborhood, or a custom built wheel chair he would tow people on with his truck or pit bike in the desert. Obviously Jake would typically be the first one to test out whatever they built.

To Jake, mechanics came easily. Working on his trucks was a passion of his and when something broke Jake would do his research and find a way to fix it. He once slaved over rebuilding his diesel truck's engine all by himself from bottom to

top with no prior diesel mechanic education after it blew up. To our disbelief it was up and running better than ever in just two months.

Jake was in the process of building his prerunner truck and swapping the engine in it from a stock 3.0L V6 to an LS1 with over 500 horsepower in preparation to compete at Jump Champs in Glen Helen this upcoming season. His Dad and his friends will continue to build the truck how Jake wanted. Jake's Dad plans to compete in Jump Champs in Jake's honor once the truck is completed.

One of Jake's favorite places in the whole world was Lake Havasu City, Arizona. He loved being on the lake and driving his family's Magic boat. He planned to eventually move there in the near future.

Jake is survived by (Mom) Kathy, (Dad) Ken, (Sister) Alexis, (Grandparents) Bill, Jo, Chuck, Victoria, (Cousins) Aimee-Tony, Heather-Garen, Dillon, Merik, Kyle, Ryan, Laura, Leah, (Aunts) Tracey, Kara, Kelly (Uncles) Eric, Mike, John and hundreds of amazing friends.

Jake's services were held together with Blake Dingman (a best friend of his who also lost his life in the Borderline shooting) at Calvary Community Church, 5495 Via Rocas in Westlake on December 8th. To donate directly to the family, please go to <https://www.gofundme.com/tjm6hg-dunham-family>

MUJERES ENLAZADAS POR SANGRE



Mujeres Enlazadas por Sangre se reunieron en Maggiano's en Costa Mesa el martes, 14 de agosto de 2018 para aprender acerca de superar los desafíos presentados por Pfizer. Las damas que asistieron pudieron aprender cómo lidiar y manejar durante situaciones estresantes y aprender unos de otros. Durante esta presentación, las mujeres también disfrutaron de una deliciosa cena italiana! Gracias, Angelica Flores y Patty Eastin y todo el equipo de Pfizer por tener una sesión de inglés y español disponible para nuestras maravillosas damas en asistencia!



Hematology
Support Center

Your treatment is a must. Support should be too.

Learn about the ways the Hematology Support Center (HSC) can help. Find out if any of Shire's assistance programs are right for you.



Get the details on HSC including:



CoPay Assistance

You might be eligible for up to \$12,000 a year in CoPay support with our CoPay Assistance Program



Insurance Support Services

Contact HSC if you experience a delay or denial in coverage to learn about available support options. HSC can also help you navigate insurance options.

Support designed with you in mind.

Patient: Call 1-888-229-8379 or visit hematologysupport.com.

HCP: Call 1-855-229-7377 or visit hematologysupportpro.com.

© 2018 Shire US Inc., Lexington, MA 02421. All rights reserved. 1-800-828-2088.

SHIRE and the Shire logo are trademarks or registered trademarks of Shire Pharmaceutical Holdings Ireland Limited or its affiliates. The Hematology Support Center Logo is a trademark of Baxalta Incorporated, a wholly owned, indirect subsidiary of Shire plc.

S39346 04/18





MEMBER SPOTLIGHT: JORDAN BURNS

By KT and Mike Burns

Football? We didn't need to look up the sports rating to know that it's a high-risk sport. What we didn't know was that it would be the most rewarding introduction to high school for our son, Jordan.

As parents of a son with moderate hemophilia, who is not on prophylaxis, we expected to be told "No" by the school and his hematologist. Even the voice inside our heads were questioning the idea. What decisions had we made to get us to this point in our lives?

Like mostly every other kid in Southern California, Jordan started with soccer when he was five years old. On Jordan's first team, he was taller than other kids and was picked to be goalkeeper. Throughout the AYSO seasons, he often played goal. It was safe, fun, and he was really good at it. Around age 10, Jordan started playing club soccer. We were concerned that stronger kids and a faster game might lead to more injuries. We needed more knowledge from people who had similar experiences. Around that time, we became members of the Hemophilia Foundation of Southern California.

HFSC provided the resources we needed. We've talked with many of you about your experiences with sports and high school. One seminar at a Blood Brothers event discussed sports.

In particular, the value of sports as part of a healthy lifestyle – one where good muscle development helps minimize joint bleeds. The seminar also discussed how organized sport, where teams are evenly matched in skill, are safer than ad-hoc games with friends.

Jordan did get a few more injuries each year playing soccer, but was also staying fit, with two practices and a game every week. He was also becoming an excellent goalkeeper.

The soccer matches continued to get faster and, as the boys got older, more aggressive. Our comfort level with soccer was declining. Although goalkeeper is a pretty safe position, the risks were increasing. Jordan hadn't yet learned to self-infuse, as he only needed to infusions a few times per year. At this point, Jordan had his first camp experience at The Painted Turtle. Two days after coming home, he used his new self-infusion skill following a soccer match where he jammed his finger. Previously, this would have required a trip to the emergency room.

This past spring, Jordan had his introduction to high school night. As part of the introduction, new students were invited to sign up for sports. Jordan has always loved football. In addition to soccer, he's played flag football, and is an avid fantasy football player. He hesitated before signing up. He knew he wouldn't be quarterback, or defense, or 98% of the other positions. But there was one position however which is safer than the others and would leverage his soccer goalkeeper skills – kicker. We knew we had a few months to change our mind. Months later, the initial team meeting was held.

"I've coached for 20 years. You can ask me anything. I've heard it all," Coach Gibson said during the introduction. "Our son has a bleeding disorder, but wants to play football," we replied. He hadn't heard that before.

We met with the coaching staff, school nurse and administration to discuss Jordan playing football. The group listened carefully to our story of Jordan's skills and limitations. Given the right precautions, we had every confidence that this could be done safely. "No" would have been an easy and understandable answer, but instead they agreed to work with us, providing they had approval from his hematologist. We met with his hematologist the next week.

"Jordan would like to play high school sports," we said, admittedly trying to postpone the conversation. When we said that he was interested in playing football, she was skeptical. We asked if prophylaxis was an option to mitigate the risk. Nope – not worth the risk of developing an inhibitor, she said. We understood her position. "Sports?" she said, emphasizing that we had used the plural. "Chess," we said. Jordan is also a fine chess player. She was ok with that.

"No contact sports" was the direction of his hematologist. Although Jordan had trained diligently throughout the summer, it looked like his football dream was over. The regular season started the following week and Jordan wouldn't be allowed to play.

Coach approached Jordan after the last summer practice. "We have a position open for Team Manager," Coach informed Jordan. Yes! Jordan would receive all the benefits of training, help manage the team during games and get to socialize with the new friends he had made over the summer.

The football season has come and gone. The experience of being on the freshman football team has been the best introduction to high school that one could imagine. Jordan has learned first-hand about the game he loves, and the dedication required by those that play it. Off the field, the football program has been teaching the players how to work together to support causes which benefit the school and the community.

As parents, we've seen our son's growth in the responsibility he's taken to ensure success in both sports and academics. We'd like to thank our allies from Woodbridge High School – Coach Gibson, Coach Colbert, the Warriors football program, and the Health Office and Administration for making his dream possible.



WINGMEN FOUNDATION GOLF EVENT



Congratulations to the winners of the Wingmen Foundation Inspiring Shots Golf Tournament at CSL Behring's Junior National Championships in Arizona. Team SoCal took the win of a \$2500 donation to their local chapter, Hemophilia Foundation of Southern California. Congratulations to Harp and Gene for putting on a great competitive demonstration of golf within the bleeding disorder community.

Thank you, Wingmen Foundation for your support!

DO YOU OR SOMEONE YOU LOVE HAVE HEMOPHILIA A WITH AN INHIBITOR TO FACTOR VIII?

YOU MIGHT BE INTERESTED IN OUR CLINICAL RESEARCH STUDY.

Factor VIII inhibitors are antibodies that people with hemophilia A can develop in response to their Factor VIII treatment. They interfere with Factor VIII and prevent it from working the way it should. The development of FVIII inhibitors is one of the most serious complications for people with hemophilia A.

The INITIATE clinical study is examining the potential advantages of utilizing a patient-specific laboratory test called batch-selection to decrease the time to success in Immune Tolerance Induction (ITI) for hemophilia A patients with inhibitors to FVIII.

SPEAK TO A STUDY REPRESENTATIVE

For more information, or if you would like to be considered for participation in the study, please contact us at **916-734-3880**. We will be available to discuss any concerns or answer any questions.

Or go to www.initiateusa.com to learn more.





GETTIN' IN THE GAME WITH PERRY PARKER

On August 25, 2018, CSL Behring sponsored a Gettin' in the Game golf event with pro golfer Perry Parker held at the beautiful Arroyo Trabuco Golf Club in Mission Viejo. Fresh off a flight from The Australia Legends Tour-four time winner, Perry Parker led an amazing Saturday morning golf clinic at his beautiful club! Thank you Perry- what an honor and privilege for us to learn from you and we are so grateful for both your local financial support (with your generous donations to HFSC in the thousands of dollars to support our scholarship fund) and dedication to the bleeding disorders community at large. You are an inspiration to all. Almost 40 members are now new golfers! Thank you CSL Behring for sponsoring this event and Anne McGuire and Dayami Nickel for your support!



SURF EVENT! "MAY THE WAVE HEAL US ALL"

On Sunday, September 16, 2018, over 100 participants headed to Huntington Beach for the HFSC Staycation and Community Beach Day. In addition to visiting sponsor booths, participants heard "Riding the Gnarly Wave of Life" by speaker Dr. Shawn Whelan, and "The Benefits of Staying Fit and Prophylactic Care" by Dr. Doris Quon of Orthopaedic Hemophilia Treatment Center and Dr. Nina Hwang, Pediatric Hematologist at Center for Inherited Blood Disorders. Lunch was served courtesy of Brothers Healthcare, and then everyone moved on to beach activities and visiting sponsor booths. Due to the 8-foot swells and red flag warnings, we were unable to offer surf lessons, but the Maui Ola Foundation offered a make-up lesson to anyone who was signed up and attended the event.



Thanks to our sponsors: Bayer, CSL Behring, Octapharma, and Shire
Lunch sponsor – Brothers Healthcare

Drink, Dessert, and Snack Sponsors – Bioscrip, Oso Home Care, Diplomat, Guided Alliance, CVS Health and Advantage Infusion Care

Thank you to the Maui Ola Foundation and Kula Nalu Ocean Sports.

Thank You to Volunteers: Larry Hammerness, Michele Warner, Silvia Garcia, Charlie Inglis, Nate McFadden and Edith Mejia

NOW APPROVED

FOR PEOPLE WITH HEMOPHILIA A WITH OR WITHOUT FACTOR VIII INHIBITORS

GO SEEK. GO EXPLORE. GO AHEAD.



Discover your sense of go. Discover HEMLIBRA®.

HEMLIBRA.com

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. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. HEMLIBRA may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). 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.

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,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048

HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan
©2018 Genentech, Inc. All rights reserved.

For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.

This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised : 10/2018



© 2018 Genentech USA, Inc. All rights reserved. EMI/061818/0106
HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan.
The HEMLIBRA logo is a trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan.
The Genentech logo is a registered trademark of Genentech, Inc.
All other trademarks are the property of their respective owners.

Genentech
A Member of the Roche Group

xyntha[®] solofuse[®]

Antihemophilic Factor (Recombinant)



Not an actual patient.

**Demonstrated to control and prevent bleeds—
XYNTHA SOLOFUSE helps prepare you to live actively**



BRING IT.
Visit XYNTHA.com to learn more

What is XYNTHA?

XYNTHA[®] Antihemophilic Factor (Recombinant) is indicated in adults and children for the control and prevention of bleeding episodes in patients with hemophilia A (congenital factor VIII deficiency or classic hemophilia) and for the prevention of bleeding during surgery in patients with hemophilia A.

XYNTHA does not contain von Willebrand factor and, therefore, is not indicated for von Willebrand's disease.

Important Safety Information for XYNTHA

- Call your healthcare provider or go to the emergency department right away if you have any of the following symptoms because these may be signs of a serious allergic reaction: wheezing, difficulty breathing, chest tightness, turning blue (look at lips and gums), fast heartbeat, swelling of the face, faintness, rash, low blood pressure, or hives. XYNTHA contains trace amounts of hamster protein. You may develop an allergic reaction to these proteins. Tell your healthcare provider if you have had an allergic reaction to hamster protein
- Call your healthcare provider right away if bleeding is not controlled after using XYNTHA; this may be a sign of an inhibitor, an antibody that may stop XYNTHA from working properly. Your healthcare provider may need to take blood tests to monitor for inhibitors
- Across all clinical studies, the most common side effects (10% or more) with XYNTHA in adult and pediatric previously treated patients (PTPs) were headache (26% of subjects), joint pain (25%), fever (21%), and cough (11%). Other side effects reported in 5% or more of patients were: diarrhea, vomiting, weakness, and nausea



- XYNTHA is an injectable medicine administered by intravenous (IV) infusion. You may experience local irritation when infusing XYNTHA after reconstitution in XYNTHA[®] SOLOFUSE[®].

Please see the Brief Summary for XYNTHA and XYNTHA SOLOFUSE on the next page.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

4TH ANNUAL BACK TO SCHOOL EDUCATIONAL SYMPOSIUM



With 350 attendees, HFSC and Children's Hospital Los Angeles hosted the 4th Annual Back to School Educational Symposium in partnership with Center of Inherited Blood Disorders (CIBD), City of Hope (COH), and Orthopaedic Treatment Center (OTC) at the Omni Los Angeles Hotel on August 4, 2018. The program began with "ABC, Easy as 123, Simple as 504, IEP: The Basics of School Advocacy," presented by Sonji Wilkes, HFA. Next followed an "Ask the Expert Panel" featuring HFSC Board Members Carol Jung, Esq., Learning Rights Law Center, and Devon Rios, Esq., Rez Law Group, and Sonji Wilkes.

The Roundtable Sessions followed with topics for Preschool-2nd Grade parents moderated by Lisa Pullens, COH; 3rd-5th Grade moderated by Sonji Wilkes; 6th-8th Grade moderated by Michael Viscariello, CHLA; High School by Spencer Dunn, CIBD; Adult Transition moderated by Dr. Doris Quon, OTC; Sesión en Español Pre-K-5th Grade moderated by Cynthia Chavez, HFSC; Sesión en Español 6th-8th moderated by Lucia Lemus (COH); and Sesión en Español Preparatoria y mas allá moderated by Sandra Valdovinos-Heredia, MSW, ACSW, CHLA.

After lunch, attendees participated in an IV Infusion Practice for adults, teens and children with almost 150 people! IV Infusion nurses who helped moderate this session included Joni Oslip, NP, Bayer; Susanna Wong, RN, CHLA; Rocio Valente, RN, CHLA; Kei Chun, RN, CHLA; Belinda Sia, RN, CHLA; Lisa Pullens, RN, COH; Chris Chan, OTC; Dr. Doris Quon, OTC; Spencer Dunn, MSW, CIBD. The second breakout was "Your Voice Has Weight: Let's Advocate!" presented by Sonji Wilkes, HFA.

Children ages 0-11 enjoyed childcare all day, and teens participated in ukulele lessons from the Heartstringz Foundation. After learning the basics, teens performed "You Are My Sunshine" to the surprise of everyone! All participants took home their own ukulele.

The day ended with all students pre-K through college receiving backpacks and school supplies to start their school year off!



Whether it's education or resources,
we've got you covered. Available
24/7, nursing and social work.



Brothers
HEALTHCARE

Your Clinical Resource Team:

VERONICA DIAZ, LCSW & KELLE CARTHEY, RN

BROTHERSHEALTHCARE.COM | 800.291.1089



specialty pharmacy

(866) 643-2042

www.fidelis-rx.com



Wagner Lemus
Co-Founder



Antonio Rosas
Co-Founder

We Speak Spanish

24/7 Access to Knowledgeable Pharmacists

Our pharmacists are specialty trained in hemophilia treatment and are available to answer your questions 24 hours a day, 7 days a week.

Secure Pharmaceutical Supply Chain

Our pharmacies only source blood clotting factors from the top pharmaceutical distributors, each with world-class distribution centers. The quality and security of your drug product is guaranteed.

Compliance Monitoring & Adherence Programs

We stay in regular contact with you to support adherence to your prescribed therapy. Pharmacy staff will always confirm the amount of medication and supplies you have on hand before scheduling your next shipment.

Home Nursing Services Coordination

Hemophilia patients require high-quality care coordination and support. We will coordinate home health nursing services if required by your prescriber.

Understanding Insurance Benefits

We help you understand how to get the most out of your insurance benefits and make out-of-pocket costs as low as possible. We'll provide upfront confirmation of coverage, including pharmacy and medical benefits.



"Your preferred specialty pharmacy for the hemophilia community"



specialty pharmacy

(866) 643-2042

www.fidelis-rx.com



Wagner Lemus
Co-Founder



Antonio Rosas
Co-Founder

Hablamos Español

Acceso 24/7 a Farmacéuticos con Experiencia

Nuestros farmacistas son especializados en el tratamiento de Hemofilia y están disponibles para contestar sus preguntas 24 horas al día, 7 días por la semana.

Cadena de Suministro de Factor de Coagulación Segura

Nuestras farmacias solo obtienen el factor de Coagulación de los mayores distribuidores farmacéuticos, exclusivamente de Centros de Distribución de clase Mundial. La calidad e Integridad de su producto está garantizado.

Monitoreo de Cumplimiento de Normas y Programas de Adhesión

Nos mantenemos en contacto regular con usted para apoyar la adherencia a la terapia prescrita. Personal de la farmacia siempre confirmará la cantidad de medicamentos y suministros que usted tiene en la mano antes de programar su próximo envío.

Coordinación de Servicios de Enfermería

Pacientes con Hemofilia requieren coordinación y atención de alta calidad y apoyo. Vamos a coordinar los servicios de enfermería de salud a domicilio si es requerido por su médico.

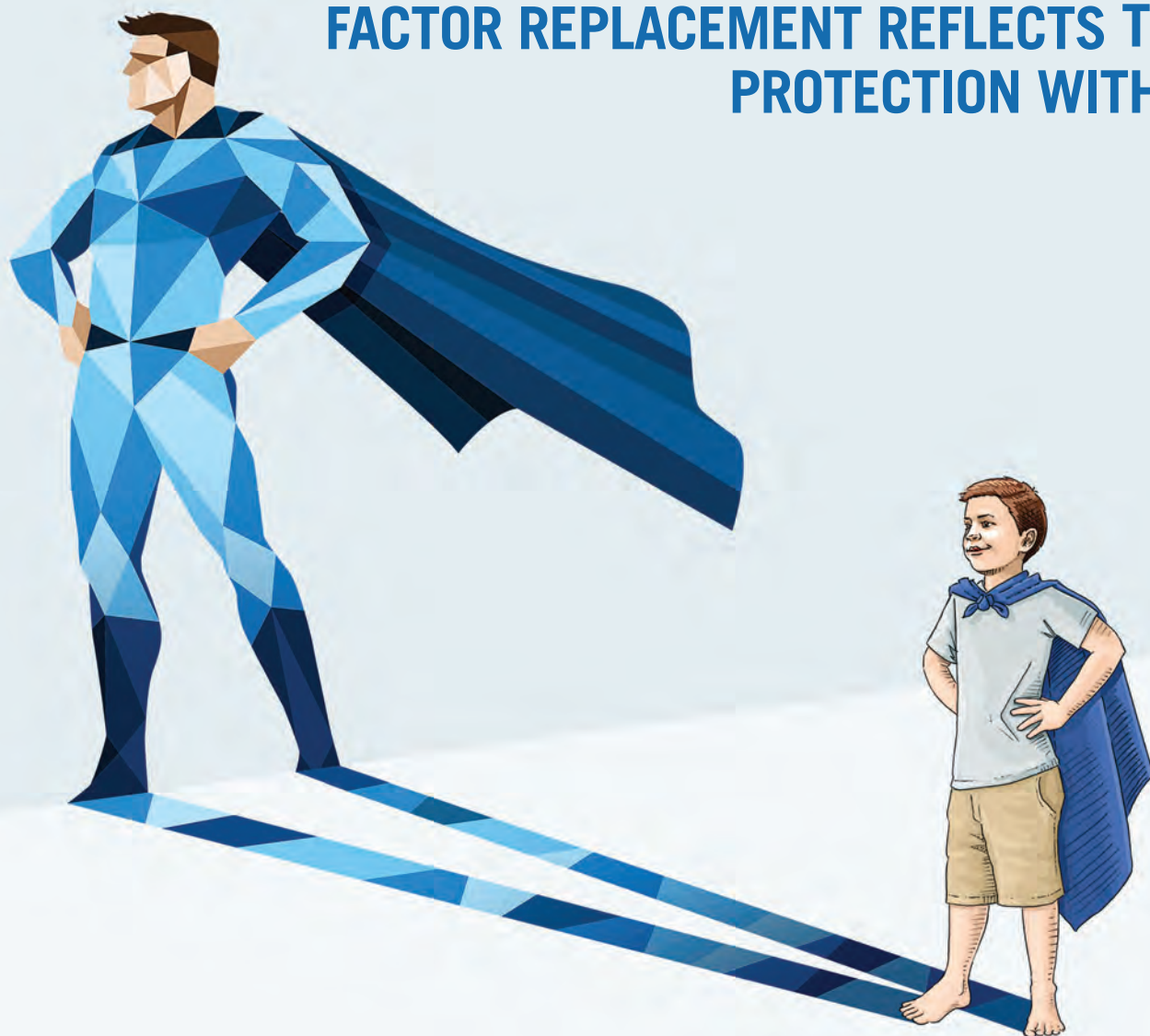
Comprensión de los Beneficios De Seguro

Le ayudamos a comprender cómo obtener el máximo provecho de sus beneficios de seguro y reducir los costos de su propio bolsillo lo más bajo posible. Ofrecemos la confirmación inicial de cobertura, incluyendo beneficios de farmacia y médica.



"Su farmacia preferida especializada en hemofilia para la comunidad latina"

FACTOR REPLACEMENT REFLECTS THE PROTECTION WITHIN



For people with hemophilia, Factor treatment temporarily replaces what's missing.^{1,2} With a long track record of proven results, Factor treatment works with your body's natural blood clotting process to form a proper clot.²⁻⁶

Brought to you by Shire, dedicated to pursuing advancements in hemophilia for more than 70 years.⁷

Stay empowered by the possibilities.

References: **1.** Peyvandi F, Garagiola I, Young G. The past and future of haemophilia: diagnosis, treatments, and its complications. *Lancet*. 2016;388:187-197. **2.** Canadian Hemophilia Society. Factor replacement therapy. <http://www.hemophilia.ca/en/bleeding-disorders/hemophilia-a-and-b/the-treatment-of-hemophilia/factor-replacement-therapy/>. Accessed May 18, 2018. **3.** Franchini M, Mannucci PM. The history of hemophilia. *Semin Thromb Hemost*. 2014;40:571-576. **4.** Hvas AM, Sørensen HT, Norengaard L, Christiansen K, Ingerslev J, Sørensen B. Tranexamic acid combined with recombinant factor VIII increases clot resistance to accelerated fibrinolysis in severe hemophilia A. *J Thromb Haemost*. 2007;5:2408-2414. **5.** Antovic A, Mikovic D, Elezovic I, Zabczyk M, Huttenby K, Antovic JP. Improvement of fibrin clot structure after factor VIII injection in haemophilia A patients treated on demand. *Thromb Haemost*. 2014;111(4):656-661. **6.** Berg JM, Tymoczko JL, Stryer L. Many enzymes are activated by specific proteolytic cleavage. In: *Biochemistry*, 5th ed. New York, NY: WH Freeman; 2002. <https://www.ncbi.nlm.nih.gov/books/NBK22589/>. Accessed May 18, 2018. **7.** Shire. Shire's 70+ year commitment to the hemophilia community. <https://www.shire.com/en/newsroom/2018/january/7sossj>. Accessed June 6, 2018.

©2018 Shire US Inc., Lexington, MA 02421.

All rights reserved. 1-800-828-2088.

Shire and the Shire logo are registered trademarks of Shire Pharmaceutical Holdings Ireland Limited or its affiliates. S40507 06/18

Shire

Hemophilia Foundation of Southern California

959 East Walnut Street
Suite 114
Pasadena, CA 91106

NON PROFIT
US POSTAGE
PAID
PASADENA CA
PERMIT 562

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!



WOMEN'S RETREAT

**Hemophilia Foundation
of Southern California**

MARCH 22-23, 2019
CROWNE PLAZA VENTURA BEACH, VENTURA, CA

For women and teen girls ages 13+
Relax and rejuvenate while learning about bleeding disorders

<https://hfscwomensretreat2019.eventbrite.com>

EmPOWERment Forum 2019



**Hemophilia Foundation
of Southern California**

FEBRUARY 23, 2019 | PICKWICK GARDENS, BURBANK

- Learn about important advocacy topics!
- Jeanne White-Ginder, mother of Ryan White, speaks
- Emergency preparedness tips
- Legislative Updates
- Youth Program: Art Therapy with famous graffiti artist

Register at: <https://hfscempowerment.eventbrite.com>

**AND DON'T FORGET TO JOIN US FOR
THE 4TH ANNUAL...**

Bloody Hot Salsa Challenge

Register for
The Salsa Challenge at:
<https://hfscsalsachallenge2019.eventbrite.com>