

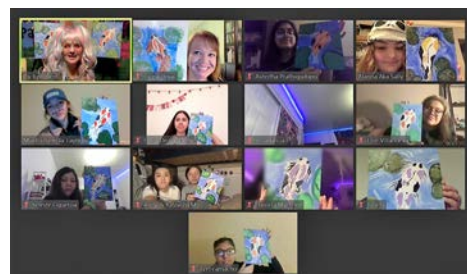
HEMOPHILIA ACTION

A PUBLICATION OF THE HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA

VOLUME 17 | ISSUE 2 | SPRING | 2021

IGNITE: WOMEN'S RETREAT 2021

HFSC hosted its 2021 Women's Retreat on 4 consecutive Wednesdays in March bringing over 150 participants together for a time of education, sharing, and laughter. The women played a lively game of Goosechase during the month where they shared talents and creativity and were treated to a lovely box filled with goodies such as a jade roller, makeup, face masks, ESPN toiletry bag and an IGNITE t-shirt. Extraordinarily talented medical providers presented an explosive array of medical information related to women's health issues and bleeding and we appreciate their advocacy efforts! It is clear more work needs to be done to push the needle forward for the best care. We want to thank our many nonprofit partners who graciously donated resources! Special thank you to Hemophilia Federation of America (HFA) for your partnership and to our HTC's for your support: Children's Hospital Los Angeles, Center for Inherited Blood Disorders and Orthopaedic Hemophilia Treatment Center. See you in person next March 2022!



Thank You To Our Gold Sponsors

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Biotherapies for Life™

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WELCOME DR. NADIA EWING TO THE BOARD OF DIRECTORS!

Dr. Nadia Ewing is the former Medical Director of the City of Hope Hemophilia Treatment Center and Professor Emeritus of the City of Hope National Medical Center. Dr. Ewing has served the pediatric bleeding disorders community in Southern California for over 40 years, participated in over 30 clinical trials for research, published over 25 peer reviewed articles, lectured nationally and abroad, and developed strong expertise in the field of inhibitors. She brings a wealth of knowledge and expertise to HFSC. She is retired and enjoys spending time with her grandchildren.

THANK YOU DONORS

General

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2021 CALENDAR

**Community Dinner:
Adversity, Strength, and Resilience**
July 14

**Virtual Camp Blood Brothers
& Sisters with The Painted Turtle**
July 23 - 25

**7th Annual Back to School
Symposium**
August 7

**Community Dinner:
Food and Fitness Basics**
August 18

**National Hemophilia Foundation:
Bleeding Disorders Conference
(virtual)**
August 25 - 28

Familia de Sangre
September 17 - 19

Cannabinoid Use for Pain and Anxiety
September 29

Unite for Bleeding Disorders Walk
November 6

HEMOPHILIACTION

is published quarterly by

**The Hemophilia Foundation
of Southern California**

In Memory

Anonymous, in memory of Ed and Betty Skinner • Ellen JS Greenberg, in memory of Irving Metz • Margarete Schwall, in memory of Michael Stone

In Honor

Harry & Juanita Boessler, in honor of Tyler, Abby and Michael Marilyn Borowsky, in honor of Cole Warner • Jane Brady, in honor of Amelie Iavicoli • Charities Aid Foundation, in honor of Diana Thomas

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A LETTER FROM THE BOARD PRESIDENT

It's an honor to have been elected as Board President and to work closely with Michelle Kim, HFSC's Executive Director, and the rest of the Board and staff. I'm excited to support the mission of the Foundation, which is to improve the quality of life for people with bleeding disorders, their caregivers, and their families.

I'm fortunate to have two children, Forrest (8) and Rowan (3), along with my wife, Joslyn. Forrest was diagnosed with afibrinogenemia (Factor 1 deficiency), shortly after he was born. Over the past several years, HFSC has played a vital role in my family's life, providing community and connection to families that are challenged with similar conditions.

With continued progress in the fight against Covid-19, it's our hope that we'll host in-person events later this year. As you might imagine, ensuring community health and safety are the top priorities for HFSC. The Foundation staff and Board are drafting policy guidelines that will allow us to meet soon based on guidance from public health experts. I'm looking forward to seeing many of you in person soon.

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

A LETTER FROM THE EXECUTIVE DIRECTOR

It has been over a year now that we have been working in a virtual space. During this time, HFSC's staff has been diligently brainstorming on best practices and opportunities to gather as a community and to provide the most relevant and effective resources. Now, with much improvement in Covid cases in Southern California, the Board of Directors is working on a plan to safely meet in person. We miss seeing everyone so much, especially the children. I also hope that you will consider signing your children up for Camp Blood Brothers and Sisters at the Painted Turtle and joining us so we can remain connected; next year, we look forward to Camp returning in person! Spring represents new beginnings and hope, and I truly wish this year is a fruitful one for all of you. We would love to hear from you too, so please stay in touch! (Michelle@hemosocal.org) Much love to all of you!

- Michelle Kim, Esq.



MY DECIDING FACTOR:

Making time for what matters most.

vonvendi
[von Willebrand factor
(Recombinant)]

Erica
Surprise, AZ
Diagnosed with VWD in 1981

**Are you ready to ask about
VONVENDI for your VWD?
Visit VONVENDI.com to
learn more.**

As an adult living with von Willebrand disease (VWD), you may share a bleeding disorder with others, but you have your own life, and your own needs. You may also have your own Deciding Factor—something that drives you to talk to your healthcare provider about finding a treatment that's right for you. For Erica, it was that her frequent bleeding episodes were taking time away from things that mattered most to her. She talked with her healthcare provider, and together they decided that VONVENDI® [von Willebrand (Recombinant)] was right for Erica's VWD.

VONVENDI

- Is used in adults (age 18 and older) diagnosed with VWD to **treat and control bleeding episodes** and **prevent excessive bleeding during and after surgery**
- **Is the first and only recombinant von Willebrand factor (VWF)**, meaning it is manufactured without human plasma or blood
- **May be used with or without a recombinant factor VIII (rFVIII)**, as instructed by your healthcare provider

VONVENDI Important Risk Information

Who should not use VONVENDI?

You should not use VONVENDI if you:

- Are allergic to any ingredients in VONVENDI.
- Are allergic to mice or hamsters.

Tell your healthcare provider if you are pregnant or breastfeeding because VONVENDI may not be right for you.

Please see additional Important Risk Information below.

Important Risk Information (continued)

How should I use VONVENDI?

Your first dose of VONVENDI for each bleeding episode may be administered with a recombinant factor VIII as instructed by your healthcare provider. Your healthcare provider will instruct you whether additional doses of VONVENDI with or without recombinant factor VIII are needed.

What should I tell my healthcare provider before I use VONVENDI?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if VONVENDI passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if VONVENDI can harm your unborn baby.
- Have been told that you have inhibitors to von Willebrand factor (because VONVENDI may not work for you).
- Have been told that you have inhibitors to blood coagulation factor VIII.

What else should I know about VONVENDI and von Willebrand disease?

Your body can form inhibitors to von Willebrand factor or factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop VONVENDI or factor VIII from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to von Willebrand factor or factor VIII.

What are the possible side effects of VONVENDI?

You can have an allergic reaction to VONVENDI.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Side effects that have been reported with VONVENDI include: nausea, vomiting, tingling or burning at infusion site, chest discomfort, dizziness, hot flashes, itching, high blood pressure, muscle twitching, unusual taste, blood clots and increased heart rate.

Tell your healthcare provider about any side effects that bother you or do not go away.

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.

Please see VONVENDI Consumer Brief Summary on the following page and talk to your healthcare provider.



Important facts about VONVENDI®:

This leaflet summarizes important information about VONVENDI. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider.

vonvendi
[von Willebrand factor
(Recombinant)]

What is VONVENDI?

VONVENDI is a recombinant medicine used to replace low levels or not properly working von Willebrand factor in people with von Willebrand disease. Von Willebrand disease is an inherited bleeding disorder in which blood does not clot normally.

VONVENDI is used in adults (age 18 years and older) diagnosed with von Willebrand disease to:

- Treat and control bleeding episodes
- Prevent excessive bleeding during and after surgery

Who should not use VONVENDI?

You should not use VONVENDI if you:

- Are allergic to any ingredients in VONVENDI.
- Are allergic to mice or hamsters.

Tell your healthcare provider if you are pregnant or breastfeeding because VONVENDI may not be right for you.

What should I tell my healthcare provider before I use VONVENDI?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if VONVENDI passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if VONVENDI can harm your unborn baby.
- Have been told that you have inhibitors to von Willebrand factor (because VONVENDI may not work for you).
- Have been told that you have inhibitors to blood coagulation factor VIII.

What is the most important information I need to know about VONVENDI?

VONVENDI can cause blood clots particularly in patients with known risk factors for blood clots. Discuss this risk with your healthcare provider.

You can have allergic reactions to VONVENDI. Symptoms may include generalized itching; rash or hives; rapid swelling of the skin or mucous membranes; chest pain or tightness; tightness of the throat; low blood pressure; shock; drowsiness; nausea; vomiting; tingling, prickling, burning, or numbness of the skin; restlessness; wheezing and/or difficulty breathing; lightheadedness; dizziness; or fainting. If symptoms occur, stop using VONVENDI immediately and get emergency treatment right away.

Your body can form inhibitors to von Willebrand factor or factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, they may stop VONVENDI or FVIII from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to von Willebrand factor or factor VIII.

What are the possible side effects of VONVENDI?

Side effects that have been reported with VONVENDI include: nausea, vomiting, tingling or burning at infusion site, chest discomfort, dizziness, hot flashes, itching, high blood pressure, muscle twitching, unusual taste, blood clots and increased heart rate. These are not all the possible side effects with VONVENDI. You can ask your healthcare provider for information that is written for healthcare professionals.

Tell your healthcare provider about any side effects that bother you or do not go away.

What else should I know about VONVENDI and von Willebrand Disease?

Consult with your healthcare provider to make sure you are carefully monitored with blood tests to measure levels of von Willebrand factor and factor VIII so they are right for you.

You may infuse VONVENDI at a hemophilia treatment center (HTC), at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or HTC. Many people with von Willebrand disease learn to infuse VONVENDI by themselves or with the help of a family member.

Call your healthcare provider right away if your bleeding does not stop after taking VONVENDI.

Medicines are sometimes prescribed for purposes other than those listed here. Do not use VONVENDI for a condition for which it is not prescribed. Do not share VONVENDI with other people, even if they have the same symptoms that you have.

The risk information provided here is not comprehensive. To learn more, talk with your healthcare provider or pharmacist about Vonvendi. The FDA approved product labeling can be found at https://www.shirecontent.com/PI/PDFs/VONVENDI_USA_ENG.pdf or call 1-800-828-2088.

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.

Issued 02/2019

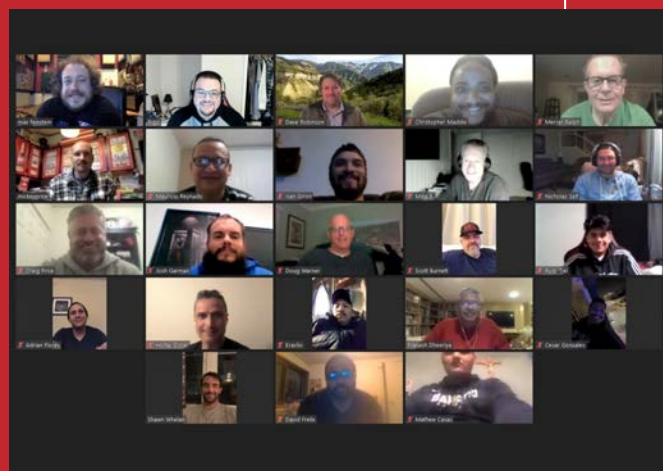
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BRO MEETING: BLEEDERS REACHING OUT

BRO continues to meet bimonthly and, on February 10th, an amazing group of 30 men gathered to check in and chat. Thank you, Dave Robinson for sharing tips on setting New Year's resolutions in times of isolation and moderating this special group. We are very grateful to the Hemophilia Federation of America for their partnership for this event! Thank you to ESPN for donating ESPN duffle bags which included the BRO logo and were given out to all the men participating. Interested in joining the next BRO check in and chat? Check out the events page on our website!



COVID TOWN HALL MEETING

On February 22, 2021 HFSC held an incredibly informative COVID Town Hall meeting with over 50 participants. The topics included the virus, vaccines, and new variants with three amazing Medical Directors: Dr. Doris Quon, Orthopaedic Treatment Center, Dr. Guy Young, Children's Hospital Los Angeles, and Dr. Amit Soni, Center for Inherited Bleeding Disorders. HFSC appreciates their support of the bleeding disorder community!



We strive to help improve the lives of people with hemophilia

For 30 years, Novo Nordisk has been a driving force for people living with rare bleeding disorders. We take pride in striving for innovative solutions to help improve patients' lives. This motivates us to uphold the highest standards in our product research and development. This vital research is just the beginning of our commitment in hemophilia.

We will continue our research and connect with people with hemophilia and health care professionals to ensure we understand and respond to the specific needs of the hemophilia community.

With a rich history, Novo Nordisk remains at the forefront of discovery. We are poised to continue to develop innovative solutions that can help improve the lives of people with hemophilia in the future.

Please visit www.rarebleedingdisorders.com or find us on Facebook at www.facebook.com/ChangingHemophilia

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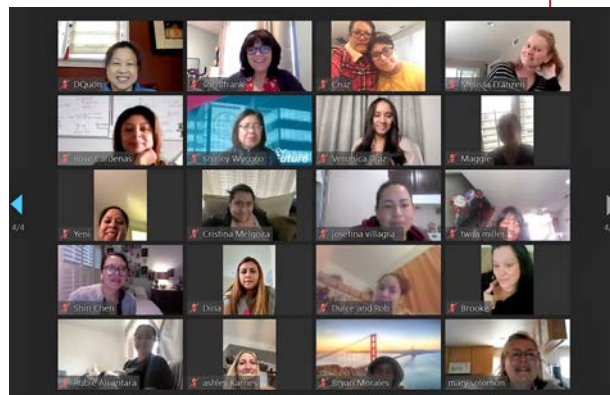
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changing
hemophilia™



2021 INDUSTRY FORUM

On Saturday, January 23, HFSC hosted its annual Industry Forum, this year virtually. For one week prior to the conference, attendees played a scavenger hunt on the Goosechase app, with the top 11 participants winning gift cards for their answers. Members shared photos and videos of best dishes, lip syncing and friends they have made over the years. Then, on the day of the event, more than 100 attendees visited a virtual exhibit hall and interacted with sponsors while playing a booth trivia game. The main session began with a welcome from HFSC, followed by breakout sessions attendees could choose from to learn more about products and services available for their bleeding disorder.

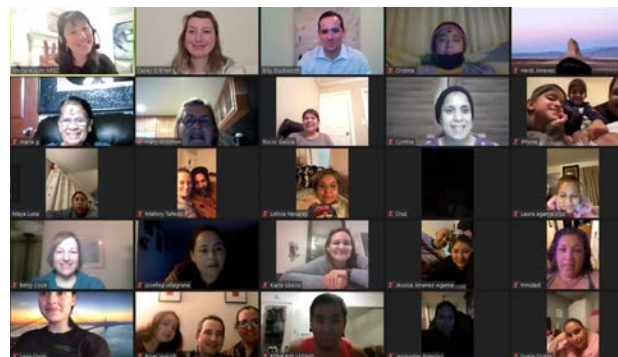


Thank you to our amazing volunteers for assisting virtually with this event, and to HFSC's Medical Advisor, Dr. Doris Quon, for hosting a booth answering questions about clinical trials.

Thank You To Our Platinum Sponsors



BOMARIN



GENE THERAPY JEOPARDY GAME

More than 50 HFSC households joined us on Wednesday, February 17 for a fun and interactive gene therapy "Jeopardy" game. It was very exciting to see all families interact and compete; we were inspired by how much our community already knows about gene therapy! We are grateful to BioMarin, Billy Duckworth and Dr. Guerrero for supporting such an informative and educational presentation.

*In Loving
Memory
of Jeremy*

The Southern CA Bleeding Disorders Community
expresses its deepest sympathy to the Sweeney
Family including wife, Kim and daughter, Rachael.

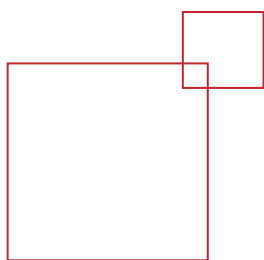


MARCH IS

BLEEDING DISORDERS AWARENESS MONTH



Thank you to all who donated, in honor of **Bleeding Disorders Awareness Month!** Because of your generous support, we raised over **\$10,000** to help us provide **scholarships** for our community members!



VIRTUAL 2021 WASHINGTON DAYS

During the first week of March, close to 400 members of the bleeding disorders community met virtually with their elected officials during Washington Days! HFSC community members attended and advocated two major issues that help improve the lives of everyone within the bleeding disorders community. First, we requested a continuation of funding for Federal Bleeding Disorder Programs. There are various federal programs that further research, enhance prevention and access to care for all those living with inherited bleeding disorders and include the National Institutes of Health (NIH), National Heart Lung and Blood Institute (NHLBI), Centers for Disease Control and Prevention (CDC), and the Health Resources and Services Administration (HRSA). The second issue was to ask our legislators to co-sign a letter to President Biden to roll-back a regulation allowing for the exclusion of co-pay assistance funds to count toward deductibles. We appreciated the hard work of all our advocates and will keep you posted!



INYO COUNTY BOARD OF SUPERVISORS MEETING

Indigenous populations and those living in rural communities with bleeding disorders may face obstacles to diagnosis, treatment, and care. HFSC thanks the Inyo County Board of Supervisors for recognizing and issuing a proclamation on behalf of our community and promoting awareness for those living with rare bleeding disorders. This is the first time HFSC has received this recognition in Inyo County, and we are grateful for your support and service. Thank you also to the community members who joined us virtually to accept this proclamation!

5° ANUAL



17-19 DE SEPTIEMBRE DE 2021

EVENTO VIRTUAL



¡Esperamos verlo en septiembre en la conferencia de desórdenes sanguíneos de habla hispana más grande del país!

HORARIO

**VIERNES
9/17**

Ceremonia de bienvenida, sala de exhibición virtual, conciertos y juegos familiares

**SABADO
9/18**

Sesiones educativas en vivo y sala de exhibición virtual

**DOMINGO
9/19**

Presentaciones de actualización de la industria, sala de exhibición virtual y sesión de clausura

TEMAS



Terapia
Génica



Inmigración



Mujeres y
desórdenes sanguíneos



Salud
Mental

CAJAS DE LA CONFERENCIA

Cada familia inscrita recibirá: una caja de pre-conferencia llena de obsequios del Salón de Exhibición, Programa de FDS, Camiseta de FDS y una tarjeta de Walmart de \$ 150 por hogar que se enviará por correo electrónico después de la conferencia.

¡LA INSCRIPCIÓN YA ESTÁ ABIERTA! REGÍSTRESE GRATIS EN [HTTP://FAMILIADESANGRE.VFAIRS.COM](http://FAMILIADESANGRE.VFAIRS.COM)

PATROCINADOR DE TITANIO



PATROCINADORES DE PLATINO



PATROCINADORES DE ORO



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GO SEEK. GO EXPLORE. GO AHEAD.

PEOPLE LIKE YOU. STORIES LIKE YOURS.
Explore more at HEMLIBRAjourney.com



Discover your sense of go. Discover HEMLIBRA.

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

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HFSC BOARD MEMBER, DR. PEDRO SANCHEZ'S WORK IN RARE GENETIC DISORDERS

3D Cameras Could Help Diagnose Rare Genetic Diseases

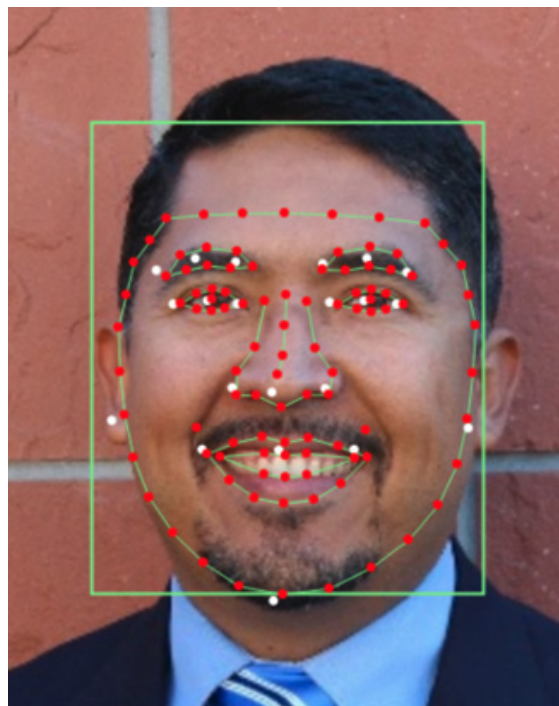
Approximately 7,000 known rare genetic disorders affect humans. Many are difficult to diagnose in infants and children, except through costly DNA tests. A Cedars-Sinai investigator is leveraging an unexpected instrument as an alternative or complement to genome sequencing: a 3D camera.

About 40% of genetic syndromes affect the shape of a person's face. Specialized physicians can recognize many by sight, but most are too subtle to be diagnosed in newborns. Pedro Sanchez, MD, a pediatrician and director of Medical Genetics at Cedars-Sinai, is studying whether a 3D-camera-created "facial atlas," paired with machine-learning software, could offer a definitive diagnosis.

With support from the National Institutes of Health, Sanchez and colleagues across the country compiled a database containing 3D photos of more than 3,000 patients with confirmed diagnoses of almost 400 conditions and, for comparison, 3,000 images of unaffected family members. (The images in the secure, private database are not associated with patients' names or personal information.) The physicians then trained analytic software to recognize the subtle facial features common to patients who share a condition. The software achieved nearly 80% accuracy in diagnosis. Sanchez hopes to expand this effort and develop a program to assist physicians in the clinic.

Although genetic conditions are often lifelong and incurable, a confirmed diagnosis, especially an early one, can help families access support and disease-specific genetic counseling. For example, patients with Beckwith-Wiedemann syndrome are more at risk for childhood cancer—with an early diagnosis, families can see a pediatrician for regular tumor screening and other proactive care.

Reprinted with permission, Sanchez, Pedro. "3D Cameras Could Help Diagnose Rare Genetic Diseases," Cedars Sinai, Discoveries, 26 February 2021, <https://www.cedars-sinai.org/discoveries.html>



COMMUNITY SPOTLIGHT: NATHAN MERMILLIOD



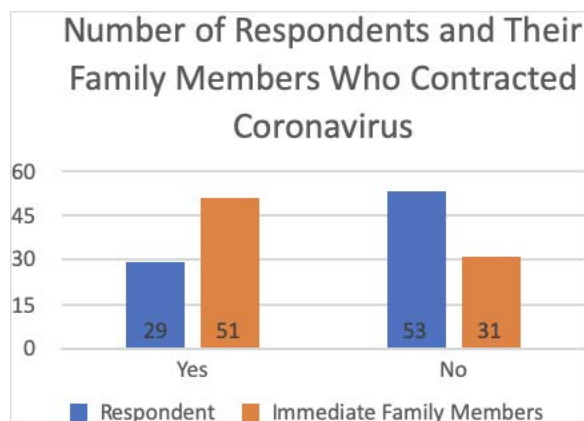
Nathan Mermilliod has been educating peers, teachers, and community members for over 12 years with presentations focused on spreading awareness and advocating for the bleeding disorders community. Now as a Freshman at Chapman University majoring in Biology, he recently partnered with the Transportation Security Administration (TSA) to prepare and deliver a first of its kind presentation on hemophilia awareness and the travelling needs of the bleeding disorders community. Presented at Los Angeles International Airport (LAX), it was simultaneously cast to a virtual audience at all the L.A. "spoke" airports - Los Angeles, Long Beach, Orange County, Ontario, and Palm Springs - and filmed by the LAX Media Team for preparation as a training video. The launch was timed to coincide with Bleeding Disorders Awareness Month and released to a TSA audience at the spoke airports in March 2021.

Nathan actively manages his dedicated Instagram page @hemophilia_grounded, and you can see his TSA training presentation on YouTube: <https://www.youtube.com/watch?v=FDG4hcpCmaE>.

COVID COMMUNITY SURVEY

by Michelle Kim; Graphic Data provided by Volunteer Xoshil Chen

Southern California and more specifically, Los Angeles County, was considered by many to be the epicenter of the post-Christmas surge during the long pandemic, and the dreaded result shocked many: 1.24 million cases and almost 25,000 dead as of June 1, 2021. LA County deaths alone accounted for more than 1/3 of all deaths in California. Even worse, by mid-January, someone was dying every 8 minutes from the virus. Underscoring what is already known about health disparities, the virus catastrophically killed Blacks at twice the rate and Latinos at three times the rate as White residents during this time. Moreover, while families struggled with death and illness, many more suffered deep financial loss, students' education was stifled by online learning and mental anxiety, stress and depression struck many who already face chronic rare illness.



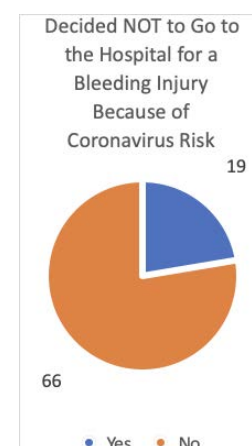
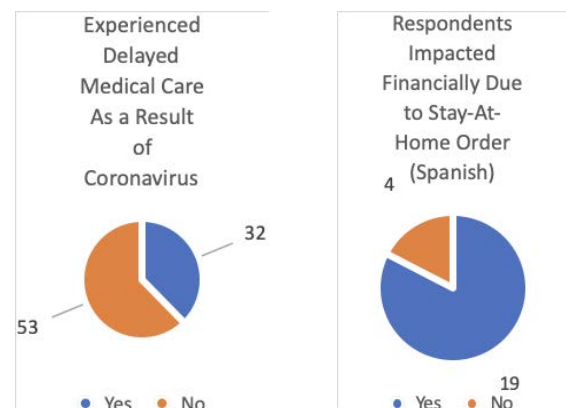
From mid-February to mid-March of 2021, HFSC released a COVID-19 community survey to measure the impact of COVID-19. 61 respondents in English and 24 in Spanish answered for a total of 85. Significantly, 64.6% of all respondents said that they or an immediate family member contracted the virus. Notably, 19.4% of respondents who contracted Coronavirus indicated they have had long-term side effects including: loss of smell; feeling excessively winded by simple tasks; very low energy and extreme fatigue; back, chest, joint, and lung pain; and severe headaches.

As with many families across the country, the pandemic negatively impacted a large portion of our community. 60.7% of respondents were financially impacted due to Coronavirus primarily by way of job loss and missed mortgage and rent payments. Unsurprisingly, the majority of these respondents made from \$25,000 to \$49,999. Additionally, a troubling data point is of the respondents who chose to complete the survey in Spanish, 82.6% were financially impacted by the Stay-At-Home Order. Further, within our community, many faced medical challenges.

The most common response to COVID-19's impact on access to care related to difficulty scheduling appointments, anxiety/fear of seeing the doctor or hospital in person, and the shortage of available appointments. Several responses noted challenges with prescription refills and routine medical care.

In conclusion, resources need to be directed to those who are still facing significant economic challenges, those needing medical care who need to now "catch up" and visit doctors, physical therapists, dentists, etc., and addressing health disparities aggressively to ensure that all receive the treatment they need.

During the pandemic, HFSC diligently made best efforts to support the community by quickly moving all educational events online, providing four townhalls to provide education about the virus and vaccines and distributing \$40,000 in 2020 in emergency financial aid and technology support. It is our hope that as more people are vaccinated and the rate of infection decreases, the lives of all impacted by this horrid virus and rare bleeding disorders continue to improve and we can be together again in person. HFSC seeks to be an added resource to our local community, and we encourage anyone needing assistance to reach out to us at 626-765-6656. Thank you to all who participated in this important survey!



CAMP AT HOME: FAMILY CAMP

JULY 23-25, 2021

Register:

www.thepaintedturtle.org/post/camp-at-home-weekend-hemophilia



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LET'S GO



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- 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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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!



HFSC OLYMPICS

LET THE GAMES BEGIN

HFSC'S UNITE FOR BLEEDING DISORDERS WALK
NOVEMBER 6, 2021 • 9 AM-1 PM • GRIFFITH PARK

<https://www.uniteforbleedingdisorders.org/event/socal>



Hemophilia Foundation of Southern California

7TH ANNUAL BACK TO SCHOOL SYMPOSIUM

AUGUST 7, 2021 | 9:00 AM-12:00 PM
VIA ZOOM

LEARN ABOUT CREATING YOUR 504 PLAN, INDIVIDUALIZED HEALTH PLAN AND INDIVIDUAL EDUCATION PLAN. JOIN IN BREAKOUT DISCUSSIONS BY GRADE LEVEL.

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