Infusions

SPRING 2021

MIKE'S AUTO BODY/FARMERS INSURANCE CAR GIVEAWAY

My Experience

By Nicholas DeFalco

I initially wasn't going to sign up for this car giveaway but after my mom insisted that I do on multiple occasions, I eventually listened to her and applied right before the deadline. Well I'm glad she bugged me because now I have a beautiful, like new 2016 Honda Fit that is great on gas and can safely take me to my far away doctor appointments. Not only that but Farmers hooked me up with a free year of insurance and my buddies at Mike's were kind enough to add some fun stuff in the trunk: a bowl of assorted candy, special oils and sprays for men, bath salts, cleaning supplies for the car, and a warm blanket that I sleep with today. I came there at 50, I left at 100.

When my mom and I arrive at the event, I meet some new people and see some of my old friends too. There are chocolate chip cookies, sodas, fruits and crackers for everyone to eat. I eat a cookie and drink soda and chat with folks, most wanting to congratulate me on my being chosen to receive the prize. I meet the other prize winner, Javier, and talk to him briefly. I meet Sal, one of the head honchos at Mike's and the man who made the big call to let me know the good news. I still remember getting the call, and my reaction to it: "Are you serious?! Omg thank you so much I can't believe it!!!" I make sure to thank him for picking me when I finally meet him.

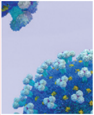
I can tell who is from Farmers Insurance and who was with Mike's Auto Body because the former wear suits and the latter wear jackets that have "Mike's Auto Body" in red on them. I meet people from both teams, all nice and friendly and happy to congratulate me. If I forgot to thank any of you, I'm sorry, and I really appreciate everything you've done for me and the community.

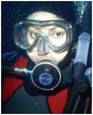
When they finally call me and Javier up to speak, I give a short speech thanking everybody and then listen to Javier's speech. By the way, both the cars are covered up until both of our speeches are finished. They reveal Javier's car and it's a gorgeous dark silver sedan, Hyundai I think. Then they open up the trunk and show him the bonus prizes they generously threw in. After that, they give him his keys and move on to me.

Now my car is revealed and you know it is a 2016 Honda Fit. I'm Ecstatic to receive this because I learned how to drive in my mom's Fit when I was in high school, so I'm already comfortable with it and enjoy driving it. Finally they hand me the keys and I get in my new car. Everyone wishes me and my mom a safe journey and we drive off the lot and head home feeling very blessed.

Me and winner Javier Caro with Sal and Mike

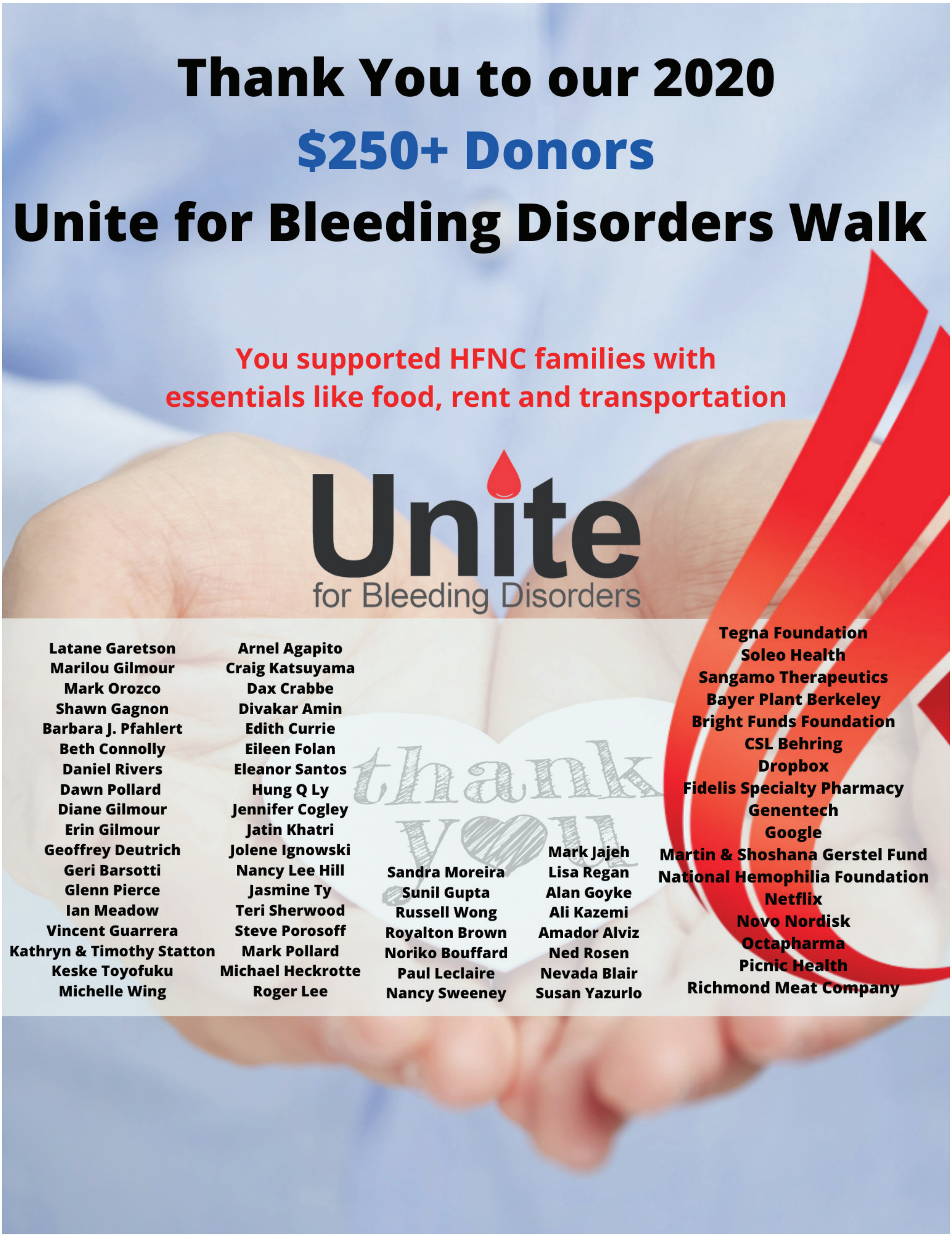
IN THIS ISSUE





NEWSLETTER OF THE HEMOPHILIA FOUNDATION OF NORTHERN CALIFORNIA

Thank You to our 2020
$250+ Donors
Unite for Bleeding Disorders Walk



You supported HFNC families with essentials like food, rent and transportation

Unite
for Bleeding Disorders

Latane Garetson
Marilou Gilmour
Mark Orozco
Shawn Gagnon
Barbara J. Pfahlert
Beth Connolly
Daniel Rivers
Dawn Pollard
Diane Gilmour
Erin Gilmour
Geoffrey Deutrich
Geri Barsotti
Glenn Pierce
Ian Meadow
Vincent Guarrera
Kathryn & Timothy Statton
Keske Toyofuku
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Sangamo Therapeutics
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CSL Behring
Dropbox
Fidelis Specialty Pharmacy
Genentech
Google
Martin & Shoshana Gerstel Fund
National Hemophilia Foundation
Netflix
Novo Nordisk
Octapharma
Picnic Health
Richmond Meat Company

SAY HELLO TO JAMES

He has hemophilia A and has gone through two major surgeries while keeping to his factor regimen with the support of his hemophilia care team

"RECOVERY WAS TOUGH, BUT I LEARNED I HAD MORE SUPPORT THAN *I THOUGHT POSSIBLE.*"

HELLO FACTOR

Read stories like James' in *Hello Factor* magazine:
BleedingDisorders.com

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Takeda

Emicizumab (Hem libra), the better Hemophilia A treatment!?

Many Hemophilia patients have switched over to the newly (ish) approved therapy of Emicizumab. This treatment has been lauded as an effective treatment that provides comparable or even superior clinical benefits to traditional factor VIII replacement therapies. It is the hemophilia "miracle" drug that is improving the life and care of hemophilia patients from 6 months-100 years old. So, what's the problem?

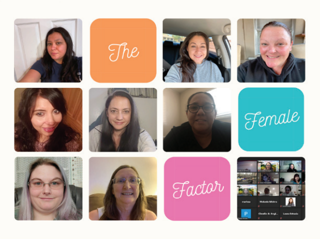
Visit compliance to put it simply. You're feeling great, doing great, haven't had a bleed in over a year so why go to the doctor? In pediatrics it is important to be seen at regular intervals to monitor the kids joints as well as growth and development. Kids change so quickly, and we need to catch any issues early to prevent long term damage. Often things are caught by those who don't see your child on a daily basis. Let me give you an example... My niece was in kindergarten and my sister thought that she was being a kid and not listening to her when she would tell her to do things. One day the teacher at school noticed that when she would say her name my niece didn't turn around or seem to even register that she heard the teacher speaking. As it turns out, my niece had drastically reduced hearing in one of her ears requiring ear tubes. My niece may have gone a few more months before this was discovered if it weren't for her teacher. When you see your Hematologist, they check your joints and make sure everything is top notch and moving in the ways that they should be and that there is no longer term damage that may be present or developing. This is also an important time to have your child weighed as they may have grown like a weed in the last few months and will require an increase in their Emicizumab dose. Other important benefits include chatting with your clinic nurse and reviewing important education points such as when to call the clinic, who to call and how to call them, and discussing lab due dates, letters needed, reviewing activity issues, reviewing joint bleed teaching, and an array of other things the nurse can help you with. The social worker is also an important clinic contact who can help you with issues that may have occurred due to copays and the need for copay programs, problems at school, social issues, etc. These are all things we can help you trouble shoot while you are at your visit.

Due to covid these visits have occurred frequently via video visits or telephone however in the future they will return to in person visits due to the more ideal nature of having a hands-on physical exam. Kaiser is currently doing a minimum of 2 visits per year with patients who have hemophilia and are on Emicizumab. This is one video visit with their primary hematologist and one hemophilia comprehensive visit. Our ideal visit frequency is every 3-4 months and the other treatment centers have similar protocols.

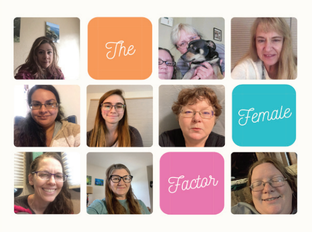
Trust me, we are as excited as you are about Emicizumab and the incredible results we have seen with it. We want you to grow, thrive, and live life bleed free. The health care teams at all the treatment centers are your advocates and want what is best for you and are here to help you reach the best possible scenario for your life. Continue your visits with your team, they are there for you.

Katie Purdy RN/CPNP/MS/CPHON
Hematology Nurse Case Manager
Kaiser Oakland

The Female Factor Retreat



November 2020



Memories

Affected and Connected

¡No necesitarás usar ninguno de estos en nuestro retiro!

You won't need to wear any of these at our retreat!

The Female Factor Retreat

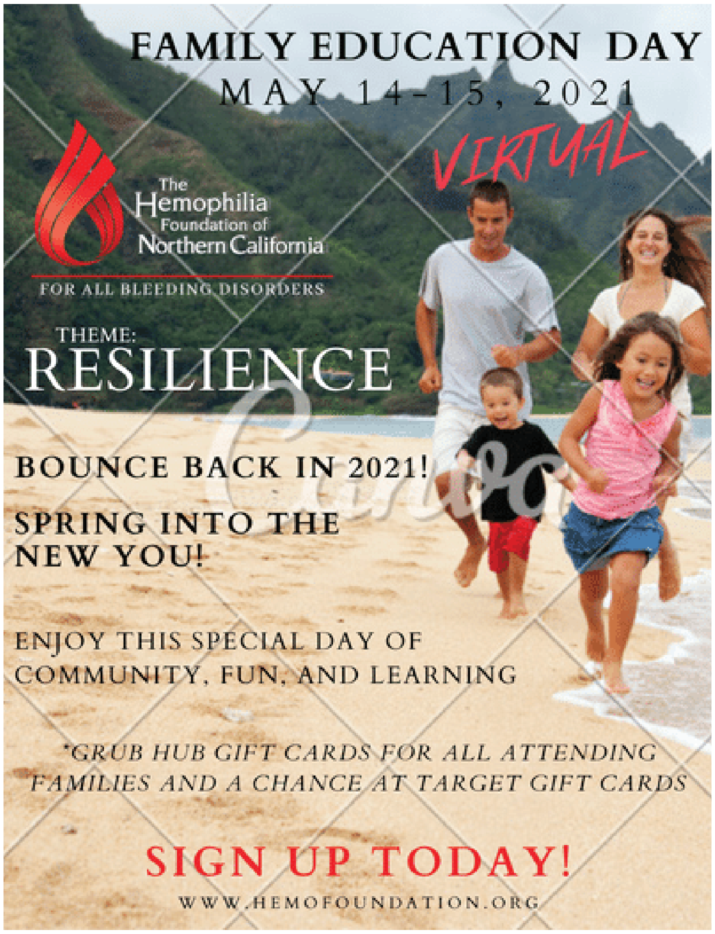
For Ages 12 & Up, Women/Identifying (at home with Zoom)
Mujeres / Identificando 12 y más (en casa con Zoom)

April 23-25   23-25 de Abril

Gift Cards   Goosechase Missions   Raffles
Event Care Package   Community Lounge

Tarjetas regalo   Rifas
Paquete Event CareSalón comunitario

Register/Registrarse at hemofoundation.org
*Must Register to attend / *Debe registrarse para asistir



FAMILY EDUCATION DAY
MAY 14-15, 2021
VIRTUAL

THEME:
RESILIENCE

BOUNCE BACK IN 2021!

SPRING INTO THE NEW YOU!

ENJOY THIS SPECIAL DAY OF COMMUNITY, FUN, AND LEARNING

GRUB HUB GIFT CARDS FOR ALL ATTENDING FAMILIES AND A CHANCE AT TARGET GIFT CARDS

SIGN UP TODAY!

WWW.HEMOFOUNDATION.ORG

Open Audition! ¡Audición abierta!

Only 3 spots   Solo 3 lugares

Share your story with an audience of your peers
Accepting auditions for
The Female Factor Retreat 2021
Opening Session
Comparta su historia con una audiencia de sus compañeros
Aceptar audiciones para
Retiro del Factor Femenino 2021
Sesión de Apertura

Submit your 2 minute video telling your story
Envíe su video de 2 minutos contando su historia

The Female Factor Retreat 2021

Deadline/Plazo 3/23/2021

Or send video to ashley.gregory@hemofoundation.org

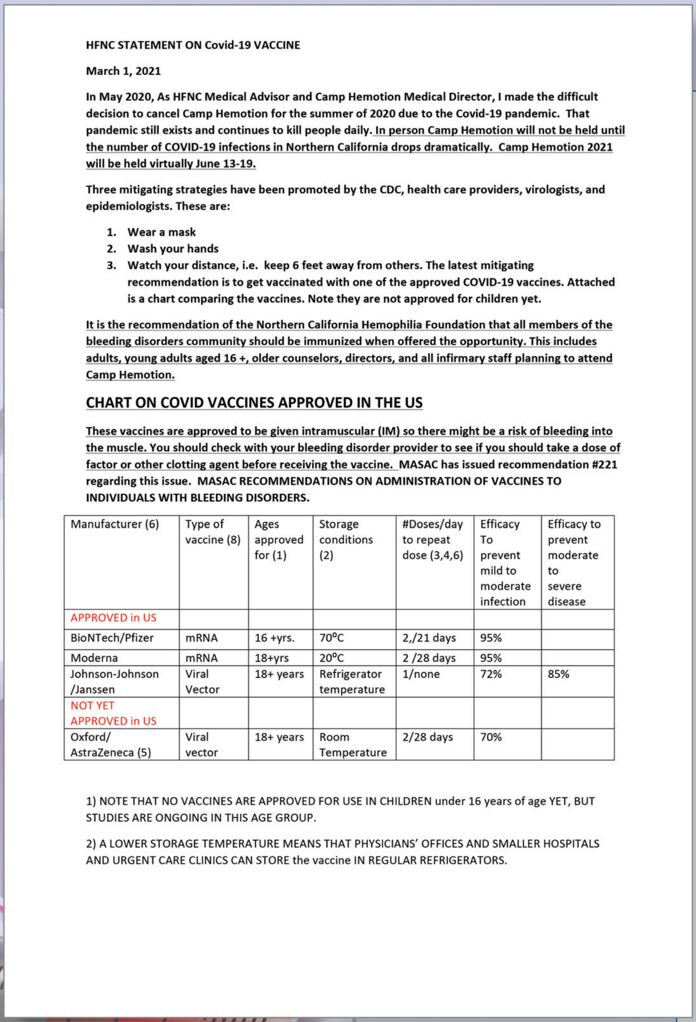
The Hemophilia Foundation of Northern California
FOR ALL BLEEDING DISORDERS

Dr. Marion Koerper

HFNC's Camp Hemotion Medical Director
Board Medical Adviser

HFNC COVID-19 Vaccine Statement

March 1, 2021



HFNC STATEMENT ON Covid-19 VACCINE

March 1, 2021

In May 2020, As HFNC Medical Advisor and Camp Hemotion Medical Director, I made the difficult decision to cancel Camp Hemotion for the summer of 2020 due to the Covid-19 pandemic. That pandemic still exists and continues to kill people daily. In person Camp Hemotion will not be held until the number of COVID-19 infections in Northern California drops dramatically. Camp Hemotion 2021 will be held virtually June 13-19.

Three mitigating strategies have been promoted by the CDC, health care providers, virologists, and epidemiologists. These are:

1. **Wear a mask**
2. **Wash your hands**
3. **Watch your distance, i.e. keep 6 feet away from others. The latest mitigating recommendation is to get vaccinated with one of the approved COVID-19 vaccines. Attached is a chart comparing the vaccines. Note they are not approved for children yet.**

It is the recommendation of the Northern California Hemophilia Foundation that all members of the bleeding disorders community should be immunized when offered the opportunity. This includes adults, young adults aged 16 +, older counselors, directors, and all infirmary staff planning to attend Camp Hemotion.

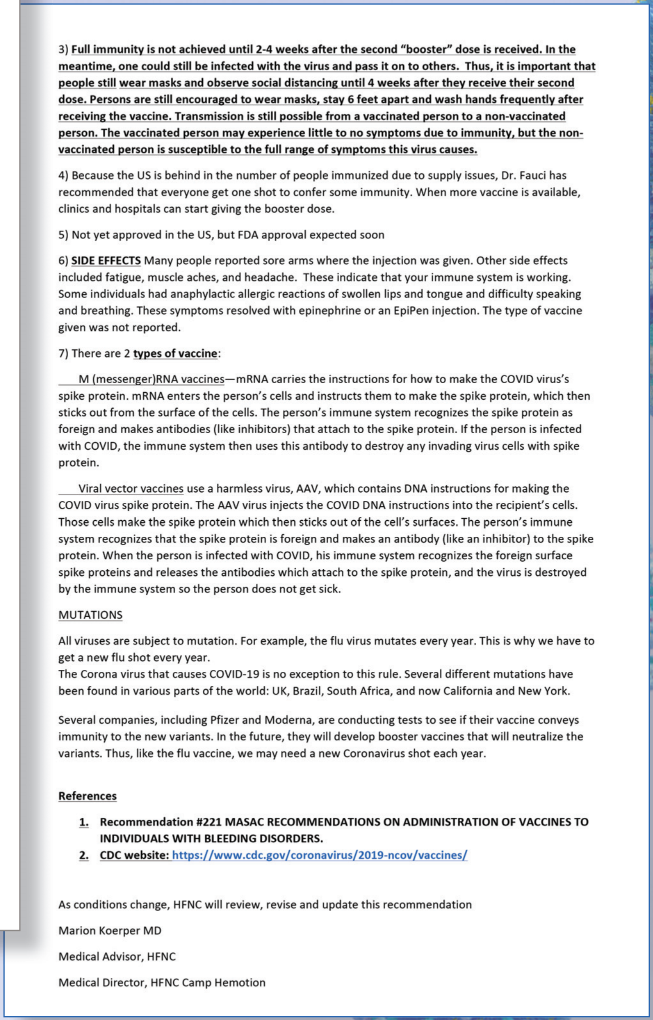
CHART ON COVID VACCINES APPROVED IN THE US

These vaccines are approved to be given intramuscular (IM) so there might be a risk of bleeding into the muscle. You should check with your bleeding disorder provider to see if you should take a dose of factor or other clotting agent before receiving the vaccine. MASAC has issued recommendation #221 regarding this issue. MASAC RECOMMENDATIONS ON ADMINISTRATION OF VACCINES TO INDIVIDUALS WITH BLEEDING DISORDERS.

Manufacturer (6)	Type of vaccine (8)	Ages approved for (1)	Storage conditions (2)	#Doses/day to repeat dose (3,4,6)	Efficacy To prevent mild to moderate infection	Efficacy to prevent moderate to severe disease
APPROVED in US						
BioNTech/Pfizer	mRNA	16 +yrs.	70°C	2,/21 days	95%	
Moderna	mRNA	18+yrs	20°C	2 /28 days	95%	
Johnson-Johnson /Janssen	Viral Vector	18+ years	Refrigerator temperature	1/none	72%	85%
NOT YET APPROVED in US						
Oxford/ AstraZeneca (5)	Viral vector	18+ years	Room Temperature	2/28 days	70%	

1) NOTE THAT NO VACCINES ARE APPROVED FOR USE IN CHILDREN under 16 years of age YET, BUT STUDIES ARE ONGOING IN THIS AGE GROUP.

2) A LOWER STORAGE TEMPERATURE MEANS THAT PHYSICIANS' OFFICES AND SMALLER HOSPITALS AND URGENT CARE CLINICS CAN STORE the vaccine IN REGULAR REFRIGERATORS.



3) **Full immunity is not achieved until 2-4 weeks after the second "booster" dose is received. In the meantime, one could still be infected with the virus and pass it on to others. Thus, it is important that people still wear masks and observe social distancing until 4 weeks after they receive their second dose. Persons are still encouraged to wear masks, stay 6 feet apart and wash hands frequently after receiving the vaccine. Transmission is still possible from a vaccinated person to a non-vaccinated person. The vaccinated person may experience little to no symptoms due to immunity, but the non-vaccinated person is susceptible to the full range of symptoms this virus causes.**

4) Because the US is behind in the number of people immunized due to supply issues, Dr. Fauci has recommended that everyone get one shot to confer some immunity. When more vaccine is available, clinics and hospitals can start giving the booster dose.

5) Not yet approved in the US, but FDA approval expected soon

6) **SIDE EFFECTS** Many people reported sore arms where the injection was given. Other side effects included fatigue, muscle aches, and headache. These indicate that your immune system is working. Some individuals had anaphylactic allergic reactions of swollen lips and tongue and difficulty speaking and breathing. These symptoms resolved with epinephrine or an EpiPen injection. The type of vaccine given was not reported.

7) There are 2 **types of vaccine**:

M (messenger)RNA vaccines—mRNA carries the instructions for how to make the COVID virus's spike protein. mRNA enters the person's cells and instructs them to make the spike protein, which then sticks out from the surface of the cells. The person's immune system recognizes the spike protein as foreign and makes antibodies (like inhibitors) that attach to the spike protein. If the person is infected with COVID, the immune system then uses this antibody to destroy any invading virus cells with spike protein.

Viral vector vaccines use a harmless virus, AAV, which contains DNA instructions for making the COVID virus spike protein. The AAV virus injects the COVID DNA instructions into the recipient's cells. Those cells make the spike protein which then sticks out of the cell's surfaces. The person's immune system recognizes that the spike protein is foreign and makes an antibody (like an inhibitor) to the spike protein. When the person is infected with COVID, his immune system recognizes the foreign surface spike proteins and releases the antibodies which attach to the spike protein, and the virus is destroyed by the immune system so the person does not get sick.

MUTATIONS

All viruses are subject to mutation. For example, the flu virus mutates every year. This is why we have to get a new flu shot every year.
The Corona virus that causes COVID-19 is no exception to this rule. Several different mutations have been found in various parts of the world: UK, Brazil, South Africa, and now California and New York.

Several companies, including Pfizer and Moderna, are conducting tests to see if their vaccine conveys immunity to the new variants. In the future, they will develop booster vaccines that will neutralize the variants. Thus, like the flu vaccine, we may need a new Coronavirus shot each year.

References

1. **Recommendation #221 MASAC RECOMMENDATIONS ON ADMINISTRATION OF VACCINES TO INDIVIDUALS WITH BLEEDING DISORDERS.**
2. **CDC website:** https://www.cdc.gov/coronavirus/2019-ncov/vaccines/

As conditions change, HFNC will review, revise and update this recommendation

Marion Koerper MD

Medical Advisor, HFNC

Medical Director, HFNC Camp Hemotion

Laura Echandi

Director - *The Female Factor*

ESTAR ENVUELTA EN LA COMUNIDAD DE DESÓRDENES SANGUÍNEOS NO FUE MI OPCIÓN ,YO NO ESPERABA QUE MI HIJO TUVIERA HEMOFILIA PERO YA QUE ES ASÍ ,DECIDÍ AFRONTARLO DE LA MEJOR MANERA. MI NOMBRE ES LAURA ECHANDI Y CUANDO MI HIJO FUE DIAGNOSTICADO A LOS 6 MESES DE EDAD , FUE ALGO MUY INTIMIDANTE LA FALTA DE INFORMACIÓN EN MI IDIOMA NO ME DETUVO Y DESPUÉS DE SIETE AñOS DE AFRONTAR LAS CONSTANTES IDAS A EMERGENCIA Y UNAS CUANTAS HOSPITALIZACIONES SIEMPRE AL LADO DE LOS CHICOS CON CÁNCER , PUDE ENCONTRAR FINALMENTE A OTRAS PERSONAS QUE COMO YO TENÍAN LOS MISMOS PROBLEMAS Y DIAGNÓSTICOS ,AHORA SE QUE HAY CAMPAMENTOS , PROGRAMAS DE EDUCACIÓN Y AYUDA ,MI FAMILIA ESTÁ CONSTITUIDA POR MI ESPOSO FEL MI HIJA LAURA Y MIS DOS HIJOS FIACH Y YANNI ,VIVO EN CALIFORNIA POCO MÁS DE 20 AñOS MI HIJO FIACH TIENE HEMOFILIA B SEVERA Y MI HIJA LAURA ES PORTADORA SINTOMATICA TENGO TRES AñOS PARTICIPANDO EN EL COMITÉ DE PLANEACIÓN , THE FEMALE FACTOR RETREAT CON HFNC (LA FUNDACIÓN DE HEMOFILIA DEL NORTE DE CALIFORNIA) DESPUÉS DE ASISTIR POR PRIMERA VEZ , QUEDÉ ENAMORADA DE LA CONVIVENCIA QUE TUVIMOS Y DE PODER SENTIRME BIENVENIDA , LOS TEMAS QUE HABLAMOS Y EL PODER CONVIVIR CON MUJERES MARAVILLOSAS ME ANIMO A FORMAR PARTE DE ESTE COMITÉ EN EL QUE CADA AñO TRATAMOS DE MEJORAR ,TRAYENDO NUEVOS TEMAS QUE SEAN DE TU INTERÉS Y PUEDAN AYUDARNOS , TAMBIÉN TENEMOS UN POCO DE DIVERSIÓN ,MANUALIDADES Y EJERCICIO COMO YOGA , ZUMBA O MEDITACIÓN. EL AñO PASADO CONTAMOS CON LA PARTICIPACIÓN DE MUJERES MARAVILLOSAS DE DIFERENTES ESTADOS Y ESTA VEZ QUIERO ANIMAR A NUESTRA COMUNIDAD HISPANA A PARTICIPAR QUIERO QUE SEPAN QUE TODAS SON BIENVENIDAS Y HAGAN ESCUCHAR SU VOZ , DÍGANOS QUÉ TEMAS LES INTERESAN Y CÓMO PODEMOS AYUDARLOS LES VOY A HABLAR UN POCO DE MI , ME CONSIDERO UNA PERSONA EMPÁTICA Y ME GUSTA AYUDAR A PERSONAS QUE COMO YO TIENEN DUDAS O NECESITAN ALGUNA ORIENTACIÓN, HE TRABAJADO EN DIFERENTES PROGRAMAS COMO VOLUNTARIA EN NHF COMO GUÍA CULTURAL LLEVANDO PROGRAMAS EDUCATIVOS EN ESPAñOL , EN VICTORY FOR WOMEN ,MyBDC , Y ACTUALMENTE EN BETTER YOU KNOW, APARTE DE SER VOLUNTARIA EN ALGUNAS OTRAS COSAS COMO PARENT NUTRITION ASSISTANT IN FRANKLIN HEAD START, COMO VERAS EL VOLUNTARIADO ES ALGO QUE REALMENTE DISFRUTO ACTUALMENTE ESTOY ESTUDIANDO FOTOGRAFIA Y CINEMATOGRAFIA , ME GUSTA BUCEAR , LEER , VIAJAR PARA CONOCER LUGARES HISTÓRICOS E IR DE CAMPAMENTO , REALMENTE DISFRUTO PASAR TIEMPO A SOLAS ,PERO TAMBIÉN DISFRUTO TENER TIEMPO DE CALIDAD CON MI FAMILIA Y AMIGOS , LO QUE MAS AMO? MIS HIJOS POR SUPUESTO, MI GRAN DEFECTO? ES QUE TENGO UNA MEMORIA PÉSIMA TENGO QUE ANOTAR TODO, CONFUNDO CARAS Y NOMBRES (TIENDO A CAMBIARLOS) ASI QUE PIDO DISCULPAS ANTICIPADAS. PARA TERMINAR POR FAVOR NO DUDES EN COMUNICARTE CON HFNC SI NECESITAS ALGO O DESEAS PARTICIPAR, YA QUE ES MUY IMPORTANTE, DESEO QUE AL IGUAL QUE YO TE SIENTAS BIENVENIDA Y QUE SEPAS QUE TU OPINION Y PARTICIPACION ES MUY IMPORTANTE PARA CREAR NUEVOS Y MEJORES PROGRAMAS.

Getting involved in the Bleeding Disorders community was not an option. I didn't expect my son to have hemophilia but once I learned of his bleeding disorder I wanted to face it in the best possible way. My name is Laura Echandi and when my son was diagnosed at 6 months of age, it was very intimidating. The lack of information in my native language was not enough to stop me. After 7 years of emergency room visits and hospitalizations alongside kids with cancer, I was finally able to find other people like me who shared the same diagnosis and faced similar challenges. I now know there are camps, education programs, and resources available to people with bleeding disorders. My family consists of my husband Fel, my daughter Laura and my two sons Fiach and Yanni. I've lived in California for more than 20 years. My son Fiach has severe hemophilia B and my daughter Laura is a symptomatic carrier. For the past three years, I have participated as part of The Female Factor Retreat committee with Hemophilia Foundation for Northern California (HFNC). From the first time I attended the retreat, I fell in love with the support I received; I felt a sense of belonging. The topics presented at the retreat and the ability to spend time with amazing women motivated me to join the committee. Every year we come together with the goal of making each year better than the last, bringing forth new talks that will interest and inform community members and offering lots of fun activities from crafts to various forms of exercise like yoga, Zumba, and meditation. At last year's retreat we had amazing women from different states in attendance, this year I would like to welcome the Hispanic Community to participate! Everyone is welcome! We want to hear your voice! Let us know what you are interested in learning and how we can be of service! I'd like to share a bit about myself. I consider myself an empathetic person. I enjoy helping others who like me have many questions and doubts and need someone to help orient me. I have experience working with various programs as a volunteer, like a Guia Cultural (Cultural Guide) for NHF, facilitating educational programs in Spanish, Victory for Women, MyBDC, and I'm currently with Better You Know. I have also volunteered as a parent nutrition assistant with Franklin Headstart. As you can see volunteerism is something I truly enjoy. I am a student studying photography and cinematography. I enjoy SCUBA diving, reading, camping, and traveling to historical places. Although I like spending time alone I also enjoy quality time with family and friends. What I love the most is my children of course! My worst weakness is I have a horrible memory. I have to note everything down and I forget names and faces; better said I confuse names and faces and continuously "change" people's names, so my apologies ahead of time. In closing please reach out to HFNC if you find yourself in need or want to get involved - it's very important! I hope I've been able to make you feel welcomed and please know that your opinion and participation matter! It's the only way we can create new and improved programs.

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
injection for subcutaneous use
150 mg/mL

Medication Guide
HEMLIBRA® (hem-lee-bruh)
(emicizumab-kxwh)
injection, for subcutaneous use

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen) or back pain
  - nausea or vomiting
  - feeling sick
  - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

See "**What are the possible side effects of HEMLIBRA?**" for more information about side effects.

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I use HEMLIBRA?

See the detailed "Instructions for Use" that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.
- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. **Do not** give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

What are the possible side effects of HEMLIBRA?

- See "**What is the most important information I should know about HEMLIBRA?**"

The most common side effects of HEMLIBRA include:

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C).
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

Keep HEMLIBRA and all medicines out of the reach of children.

General information about the safe and effective use of HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
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For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised: 10/2018

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injection for subcutaneous use
150 mg/mL

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The Hemophilia Foundation of Northern California
FOR ALL BLEEDING DISORDERS

Conoce a tu Facilitadora
Katrina Unpingco FNP-C Nurse Practitioner
UCSF Benioff Children's Hospital Oakland HTC

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HTTPS://WWW.TEAMHFA.ORG/HFNCFITNESS

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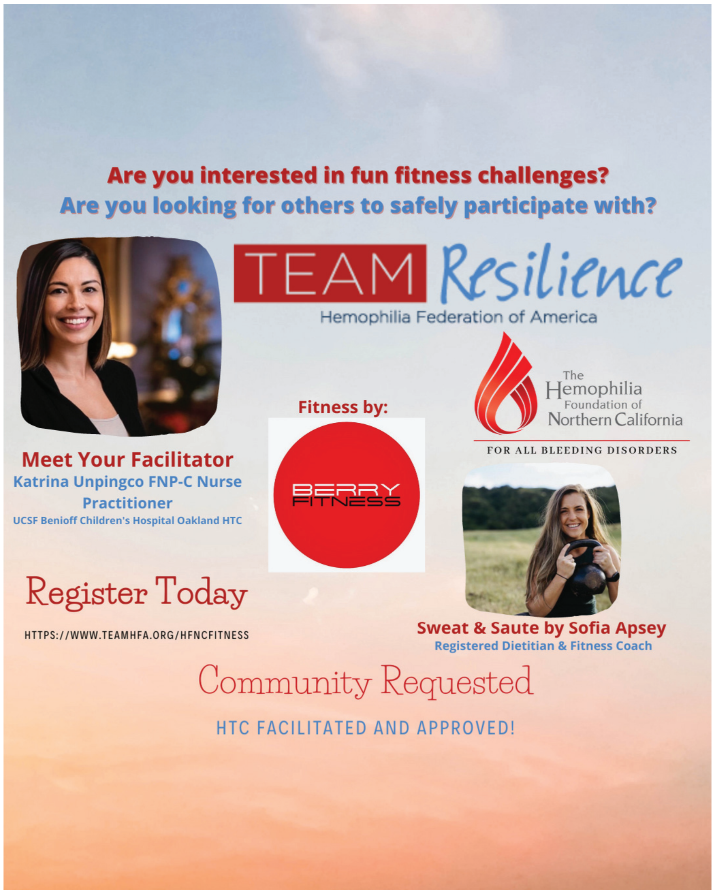

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Are you looking for others to safely participate with?

TEAM Resilience
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Meet Your Facilitator
Katrina Unpingco FNP-C Nurse Practitioner
UCSF Benioff Children's Hospital Oakland HTC

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Sweat & Saute by Sofia Apsey
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Community Requested

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Hear team stories!

One hour event online

Learn how to Register for the Unite for Bleeding Disorders Walk 2021

COME TOGETHER!
Unite for Bleeding Disorders Launch
Únase a la comunidad
Unidos por los trastornos sanguíneo

March 14 @ 1pm PST
14 de marzo @ 1pm PST

Register/Registrarse www.hemofoundation.org

Dr. Glenn Pierce

Gene Therapy Review

Revisión de la terapia genética

Dr. Barbara Konkle

My Life/Our Future Update

Actualización de Mi vida / nuestro futuro

Dr. Andrew Leavitt

Clinical Trials Update

Actualización de ensayos clínicos

Dr. Steven Pipe

New Therapies

Nuevas terapias

Keynote by Dr Len Valentino

CEO National Hemophilia Foundation

Host AnfitriónJ
Jorge de la Riva

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FOR ALL BLEEDING DISORDERS

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HEMOPHILIA COUNCIL OF CALIFORNIA

What Do Patients Need to Know about Medi-CalRx?

By Lynne Kinst, Executive Director

On April 1, 2021 California is launching Medi-CalRx, a new program which changes the way the State of California processes payments for prescription drugs, including blood factor products. Medi-CalRx will apply to bleeding disorders patients who receive services from Medi-Cal, CCS and GHPP. You may have heard about this in the news, in emails from the Hemophilia Council of California (HCC) or even in notices from the State of California or your pharmacy provider. **But most importantly, you may be concerned about what this means to you.**

Previously most medications have been paid as part of Medi-Cal Managed Care – meaning that the state paid a set rate per patient to the insurer and the insurer covers treatment and medication at contracted rates. "Fee-for-service" is when treatment or medications are paid for each service they provide. Blood factor has been "carved-out" of Medi-Cal Managed Care since 2014 and paid under a fee-for-service model, but most other medication has been under managed care. After April 1, under Medi-CalRx all covered outpatient drugs, including Physician Administered Drugs, Medical Supplies and Enteral Nutritional Products will all be paid via fee-for-service agreements. While coverage for blood factor products will be the same – the State believes it can realize significant savings on many other drugs by negotiating contracts for the large volume of drugs which will now be purchased under Medi-CalRx.

The most important fact for you to know about Medi-CalRx is that it should NOT impact your access to the medications you rely upon or the way you receive that medication. Your costs should not change. Most of the changes will take place behind the scenes – in the way that your pharmacy submits their bills to the State and how the state processes and pays your pharmacy. While the State has contracted with a new provider (Magellan) to process the pharmacy claims – unless you have made other changes to your insurance, **you should still be able to fill your blood factor and other prescription medications through the same pharmacies you have always used.**

While we don't expect you to be impacted, HCC has monitored the Medi-CalRx proposal closely since it was announced and has had multiple meetings with the State to ensure we and the pharmacies serving the bleeding disorders community understand the changes and that it will not negatively impact anyone's access to medication, but should you have any problems after April 1st – please let us know as soon as possible so we can assist you and ensure that any systemwide barriers to medication are quickly addressed.

Do you have more questions? The State has launched a website for Medi-CalRx at - https://medi-calrx.dhcs.ca.gov/home/. Patients can check out the information on the "beneficiaries" page (more information will be added to this page before April 1st) or review the FAQ for more information. As always, the Hemophilia Council of California is here to help the bleeding disorders community when you face challenges getting access to your medication or treatment. You can contact us at (916) 571-7771 or email me at lkinst@hemophiliaca.org if you need help.

The Hemophilia Council of California's mission is to improve access to care and treatment options in order to advance the quality of life for people with bleeding disorders through advocacy, education, and outreach in collaboration with our founding member organizations – Central California Hemophilia Foundation, the Hemophilia Association of San Diego County, the Hemophilia Foundation of Northern California and the Hemophilia Foundation of Southern California.

Statewide HCC represents over 404,000 people with bleeding disorders including von Willebrand disease and hemophilia. HCC helps shape state policy by educating members of the State Legislature and State regulators about what it is like to live with a bleeding disorder in an effort to maintain access to treatment, choice in treatment options and improved quality of life. HCC works to maintain funding for programs such as the Genetically Handicapped Persons Program (GHPP), California Children's Services (CCS) and Medi-Cal.

Liz Schauermann
Bleeding Disorder Territory Manager

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Soleo Health is a local provider of complex specialty pharmacy and infusion services dedicated to the bleeding disorder community and the patients we serve.

Our Bleeding Disorder Therapy Management Program is led by specialized care teams with extensive experience in Hemophilia A, B, Factor X Deficiency, Von Willebrand, and other factor deficiencies. The bleeding disorders team provides individualized services and education, which encourages your independence and enhances your care experience.

Liz Schauermann devotes her full-time work in the community to better the lives of those with bleeding disorders.

Contact Liz Schauermann, Bleeding Disorder Territory Manager, to learn more or to submit a referral:
721 S. Glasgow Avenue, Suite C
Inglewood, CA 90301
P: 866.665.1121 | F: 888.665.1141
C: 310.422.9621 | E: lseaton@soleohealth.com

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We promise

You won't be bored

At our Board Meetings!

6pm PST

Dates
3/9
4/13
5/11
7/13
8/10
9/14
10/12
11/9

Community Lounge 6-6:30pm PST
Board Stuff 6:30-7:30pm PST

Register hemofoundation.org/events

March is Bleeding Disorders Awareness Month

PUT ON YOUR
COLLEGE
RESUME

SAFE ACTIVITY

DECLARE YOUR CITY

Get your kit

Stickers
Zoom link
Awareness Postcards
Red Ties
City Declaration Template and more!!

hemofoundation.org/events

SEEKING VOLUNTEERS FOR OUR INFUSIONS NEWSLETTER

INFUSIONS

NEWSLETTER OF THE HEMOPHILIA FOUNDATION OF NORTHERN CALIFORNIA · SUMMER 2019

Camp Hemotion 2019

Match in the gas tank! BOOM BOOM. Camp Hemotion, a place where strangers become friends and friends become family. Where we all come together to sing camp songs, swim in the pool, challenge ourselves on the ropes course and our high swing. This year we took the campers out of this world to explore the stars, moon, and galaxies. From our astronaut swim to our alien hunt that was a huge hit throughout the week, we made sure that each astronaut or alien of ours had an experience to never forget.

This year was Camp Hemotion's 41st year of running their program. Being surrounded by trees, wildlife, and our Bleeding disorder family in the beautiful Coarsegold. From old traditions to new traditions, celebrating birthdays, self-infusions, and even capturing the two aliens that were roaming around our campsite! It was on the final night of camp at our campfire that we were able to reveal that the two aliens that were on our campsite were Maddy and Julian from our staff! Luckily, all they wanted to do was to bring back all the fun

Continued on Page 4

JOIN THE INFUSIONS COMMITTEE!

HELP HFNC MAKE THE QUARTERLY NEWSLETTER MAGIC HAPPEN

EMAIL ASHLEY.GREGORY@HEMOFOUNDATION.ORG

VIRTUAL CAMP HEMOTION 2021

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The Hemophilia Foundation of Northern California

FOR ALL BLEEDING DISORDERS

June 13-19, 2021

register hemofoundation.org/events

CALENDAR

MARCH

TBD	HCC Health Summit	TBD
3/1/21-3/31/21	Bleeding Disorders Awareness Month hemofoundation.org/mabdam.html	
3/3/21-4/17/21	HFA's Team Resilience Fitness Challenge teamhfa.org/HFNCFitness	
3/3/21-3/5/21	NHF Washington Days	
3/9/21	Board Meeting	Virtual
3/14/21	UNITE Walk Launch	Virtual
3/27/21-3/28/21	Family Camp	Virtual

APRIL

4/4/21	Easter	
4/13/21	Board Meeting	Virtual
4/14/21	LEG Day	Virtual
4/17/21	World Hemophilia Day	
4/23/21-4/25/21	The Female Factor Retreat	Virtual
4/30/2021	Future Leaders Weekend	

MAY

5/1/21	Bleaders	
5/11/21	Board Meeting	Virtual
5/14/21-5/15/21	Family Ed Weekend	Virtual

JUN

6/13/21-6/19/21	Camp Hemotion	Virtual/in person*
6/26/21-6/28/21	Region IX	In person/Redondo Beach

JULY

7/4/21	Independence Day	
7/13/21	Board Meeting	Virtual
7/17/21	Emerging Therapies	Virtual
7/26/21-7/30/21	HFNC Staff Strategic Planning*	In person*

AUGUST

8/1/21	Annual Mtg. & Community Picnic	In person*
8/10/21	Board Meeting	Virtual
8/26/21-8/28/21	NHF	Virtual
8/29/21	Unite Walk	In person*

HOME CHAPTER ORGANIZATION

HFNC	Hemophilia Foundation of Northern California https://www.hemofoundation.org/ Auxiliary Fresno Auxiliary San Jose

AFFILIATED ORGANIZATIONS

NHF	National Hemophilia Foundation https://www.hemophilia.org/ *NHF Chapters (See full list at NHF):*
HFSC	Hemophilia Foundation of Southern California http://www.hemosocal.org/
HASDC	Hemophilia Association of San Diego County http://hasdc.org/
CCHF	Central California Hemophilia Foundation https://www.cchfsac.org/
AHA	Arizona Hemophilia Association https://www.arizonahemophilia.org/
HFO	Hemophilia Foundation of Oregon http://hemophiliaoregon.org/
HFA	Hemophilia Federation of America http://www.hemophiliafed.org/
HCC	Hemophilia Council of California https://www.hemophiliaca.org/
WFH	World Federation of Hemophilia https://www.wfh.org/

PARTNER ORGANIZATIONS

HTC	Hemophilia Treatment Centers: Stanford University Medical Center https://www.stanfordchildrens.org/en/service/hematology University of California at Davis https://www.ucdmc.ucdavis.edu/hemophilia/ University of California San Francisco https://www.ucsfhealth.org/clinics/hemophiliatreatment_center/ UCSF Benioff Children's Hospital Oakland https://www.childrenshospitaloakland.org Valley Children's Hospital https://www.valleychildrens.org/
MFTC	Music for the Cause https://www.musicforthecause.org/

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Since we do not engage in the practice of medicine, we always recommend that you consult a physician before pursuing any course of treatment.

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