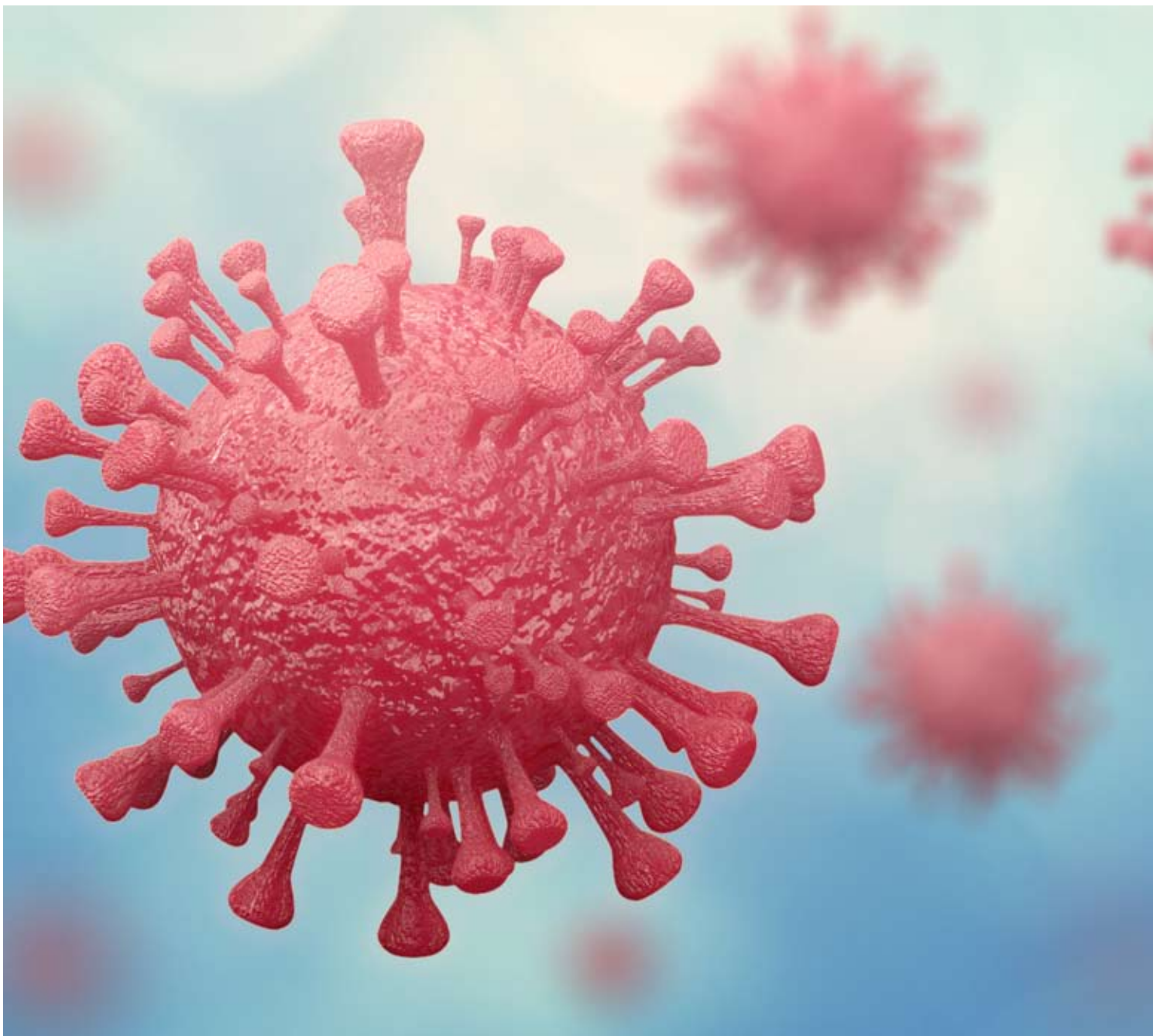




# BloodLines

The Official Newsletter of the Hemophilia Association of San Diego County | **Volume 38 Issue 1 2020**

## COVID-19 COMMUNITY UPDATE



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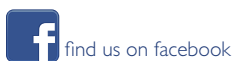
Since we do not engage in the practice of medicine, we always recommend that you consult a physician before pursuing any course of treatment.

Information and opinions expressed in this publication are not necessarily those of the Hemophilia Association of San Diego County, or those of the editorial staff.

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# DIRECTOR'S CORNER

**NOOSHIN KOSAR**  
HASDC EXECUTIVE DIRECTOR

## COVID 19 — COMMUNITY UPDATE

HASDC Community Members and Supporters,

As the world health community continues to monitor closely the emergence of "coronavirus disease 2019" (COVID-19), we want to make sure you are kept informed. You are our greatest asset and you are the heart of our mission, and your health and safety are paramount to us.

Given the uncertainty of the situation, and in order to follow the recommendations of social distancing, the HASDC office is temporarily closed. We encourage everyone to follow suite in social distancing to stay safe and healthy while being mindful of your emotional well-being.

Our goal is to keep you informed; therefore, we want to ensure the continuity of chapter communications and operations. We will continue to monitor the situation and take appropriate action in light of recommendations from local and national public health officials.

Please follow us on Facebook and Instagram for chapter updates. Please also read the following updates from our national partners:

- National Hemophilia Foundation's Medical and Scientific Advisory Council Letter to Community
- Statement from Len Valentino (NHF's CEO) on COVID-19
- Hemophilia Federation of America's online COVID-19 resources

## UPCOMING EVENTS

Per the CDC recommendation to postpone or cancel any gatherings of 10 people or more, HASDC events scheduled through May 30 are cancelled and/or postponed. At that time, we will re-evaluate the situation and provide any necessary updates.

Even though we cannot hold in-person events at this time, our mission to serve and educate San Diego & Imperial Counties will continue via e-mail, social media and virtual education events.

## TO OUR DONORS

We will be in communication with donors and sponsors of specific programs that have been postponed or need to be adjusted during this time. We are committed to meeting our donor expectations as best we can within this unexpected situation.

## OTHER UPDATES

HTC Updates | San Diego Resources

Visit the COVID-19 page on our website to find updates from our local Hemophilia Treatment Centers as well as resources on staying healthy, preparedness during this time and local San Diego resources.

## DONATIONS

You can continue to support HASDC in the following ways. All donations will be going towards our bleeding disorder families in need, in San Diego and Imperial counties, and those who request emergency financial assistance through HASDC.

- Amazon Smile: Are there items you need? Practice social distancing by staying inside and ordering through Amazon Smile. It's easy to support HASDC while you shop. HASDC will receive a minimum of 1% on all your purchases.
- PayPal: provide a direct donation via PayPal.

We appreciate your understanding and continued support during these unprecedented times. Do not hesitate to contact us with any questions/concerns: info@hasdc.org or 619.325.3570 (leave a voicemail).

Please stay healthy during this time,

*Nooshin*  
Nooshin Kosar, HASDC Executive Director



# WELLNESS CORNER

PAM MCKEIRNAN  
HASDC BOARD MEMBER



Wellness (wel-nis):  
the quality or state of  
being healthy in body and  
mind, as the result of a  
deliberate effort.

## EXERCISE FOR THE BODY AND THE MIND – YOGA!

There are a variety of yoga techniques, all giving different results. There are restful postures, Yin, which is not for strength building but rather for stretching and opening up the body. Vinyasa uses more energetic postures along with breathing. For people recovering from a bleed or injury you may want to practice Iyengar this yoga style uses assisted yoga postures, using props for support. Bikram is a type of yoga done in a hot room. The heat helps to loosen body and go deeper. All these varieties of yoga can help with pain management, confidence and stress relief. Yoga postures can easily be modified to accommodate strength, experience and health conditions. Starting slowly and gradually expanding your practice is important as to not injure or derail your progress.

The practice of yoga is a unique fitness activity as it improves mental fitness, as well as physical. Using breathing techniques and a focus on the resiliency of the mind, you can gain a better ability to cope with chronic pain. This is because yoga's healing practices – from breathing exercises to restorative poses – consider that chronic pain is a mind-body experience, and therefore must involve both of these to find true relief. Chronic pain is not unusual as one ages and has had multiple bleeds. As you practice yoga the mind and body learn to detect even the slightest threat and launch a full response to it. By focusing on the power of this mind-body connection, yoga can relax your mind and ease your body of both pain and stress, by taking away this overprotective response.

Because yoga postures can be adapted to your individual needs, it can help build body confidence, even after years of injury, physical limitations and pain. The more strength and flexibility you build in your joints will result in fewer injuries. So, each successful workout sends a reward to our brain, which we, in turn, want to replicate again the next day, circling the positive feedback loop. The better we feel in our minds, the better we will treat our bodies and vice versa.

### IS YOGA THE RIGHT EXERCISE FOR ME?

If you decide to introduce exercise into your daily routine then yoga may be right for you. Get started by signing up for a beginner's class that focuses on gentle poses and breathing. This allows more time for you to get used to yoga poses and gently work your muscles as you hold them and progress from one pose to the next. The guiding breathing will help you focus on what you are doing. It is important to start slowly so that your body can adapt to the demands of yoga and to avoid muscle strain. After practicing for a short while, you will notice that you can do things you were unable to do before. The increased flexibility of yoga can make other physical activities safer. Before starting any class, it is important to find a teacher who will listen to your health concerns. This way they can teach you poses that avoid trouble spots and will not push you beyond your limits.

Although yoga is a low-risk exercise, it is not for everyone with a bleeding disorder. While yoga is great for building strength, balance and flexibility, the poses can put too much stress on a joint. If a pose causes pain in a joint then you need to be concerned. You should exclude that pose from your routine and always follow up with your doctor. It is also good to talk to your physical therapist about any concerns so that you can get their input on the best and safest workout.

Be sure to consult with your physician or physical therapist for advice on what exercises to do – and what not to do – so that you can maximize your workout without stress or injury. Bottom line – relax and have fun!





# GO SEEK. GO EXPLORE. GO AHEAD.

PEOPLE LIKE YOU. STORIES LIKE YOURS.  
Explore more at [HEMLIBRAjourney.com](https://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. 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**.



**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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For more information, go to [www.HEMLIBRA.com](http://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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& Thrombosis  
Treatment Center

*Dr. Courtney  
Thornburg, MD, MS*

*Director  
Hemophilia  
& Thrombosis  
Treatment Center*

# TRAVEL READINESS - ADVICE FROM DR. THORNBURG

Traveling is exciting and allows for us to see new places, try new foods, and learn about people and cultures around the world.

Individuals with medical conditions, including bleeding and clotting disorders, must take extra steps to make sure that they stay healthy during travel.

Make sure you have an adequate supply of all of your regular medications. Make sure that you have enough doses and double check the expiration dates to make sure the medication will not expire during your trip.

For individuals who inject or infuse medication, make sure that you also have an adequate amount of supplies for scheduled and as needed doses.

If you have a bleeding disorder, make sure that you bring along the medication(s) that you use to treat bleeding. Even if you take prophylaxis with clotting factor or emicizumab you should bring clotting to treat bleeding or in the event of injury or emergency surgery.

It is best to carry the medications and supplies in your carry-on. Check airline specific information to determine if you need medical documentation to carry these items on board.

Ask your Hemophilia and Thrombosis Treatment Center (HTC) provider for an emergency letter if you don't already have one. This should include your individual emergency plan and contact information for the HTC.

While you are traveling it is important to know how to access emergency services if needed. There are HTCs throughout the world (<https://www.wfh.org/en/resources-education/treatment-centre-directory>) if you need special services while traveling.

If you are traveling abroad you can check the Centers for Disease Control and Prevention website for travel advisories and to find out if you need any special vaccines. The 2019-nCoV (COVID-19, novel coronavirus) outbreak is of particular concern right now. Travel advisories are constantly changing as the virus is tracked.





## UC San Diego Health Hemophilia & Thrombosis Treatment Center

*Dr. Annette  
Von Drygalski, MD,  
PharmD Director  
Hemophilia  
& Thrombosis  
Treatment Center*

# THE UCSD HEALTH – MAPUTO CENTRAL HOSPITAL COLLABORATION

In 2019, the World Federation of Hemophilia (WFH) officially recognized the effort between the UCSD Hemophilia and Thrombosis Treatment Center (HTTC) and the Hematology Department at Maputo Central Hospital in Mozambique. Thus, the programs were designated as ‘twins,’ which means that critically needed clotting factor can flow from the WFH to the hemophilia community in Mozambique, starting with Maputo Central Hospital.

Last Fall, a team from the UCSD HTTC visited Maputo to further advance hemophilia-specific physical therapy, athletic training, nursing and advanced medical care.

The goals of the visit were to advance the interdisciplinary approach to the diagnosis and care of hemophilia patients, to strengthen the operations of the local hemophilia patient association.

Hemophilia care focused on joint health with the following points:

- Joint evaluation by physical exam and by musculoskeletal ultrasound (MSKUS)
- Recognition of acute joint bleeding
- Perform Hemophilia Joint Health Score (HJHS) for longitudinal joint outcome assessment
- Management of musculoskeletal problems: physical therapy, short- and long-term joint rehabilitation, kinesiotaping and facilitating joint health and performance improvement
- Self-infusion training for nurses, patients, and the patients’ families
- Ultrasound-guided joint aspirations and injections



UC San Diego Health HTTC Team on their last day with Maputo Central Hospital



# New **HEAD-TO-HEAD** Pharmacokinetic (PK) Study Data

See half-life, clearance and other  
PK data from the crossover study  
comparing **Jivi®** and **Eloctate®**.

Visit **PKStudies.com** to find out more.

► **Pharmacokinetics** is the study of the activity  
of drugs in the body over a period of time.

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**Jivi®**  
antihemophilic factor  
(recombinant) PEGylated-aucI  
**LET'S GO**





## GUARDAR LA FECHA



## JOIN US

The Central California Hemophilia Foundation, Hemophilia Association of San Diego County, Hemophilia Foundation of Northern California and Hemophilia Foundation of Southern California are proud to bring you the fourth annual Familia de Sangre, a three-day bleeding disorders conference presented in Spanish. Educational sessions and networking opportunities will cover health care, education and support services. Space is limited.



**18-20 de septiembre de 2020**  
**Anaheim Marriot, CA**

La inscripción comienza el 1 de abril de 2020.  
Inscríbese en: [www.familiadesangre.org](http://www.familiadesangre.org)  
Use el código **EARLYBOOKING** por \$ 10 de descuento en las tarifas de registro de adultos hasta el 1 de mayo de 2020.

Registration opens April 1, 2020.  
Register at: [www.familiadesangre.org](http://www.familiadesangre.org)  
Use code **EARLYBOOKING** for \$10 off adult registration fees through May 1, 2020.



## ÚNASE A NOSOTROS

La Fundación de Hemofilia del Centro de California, Asociación de Hemofilia del Condado de San Diego, la Fundación de Hemofilia del Norte de California y la Fundación de Hemofilia del Sur de California están orgullosos de traerles la cuarta conferencia anual: Familia de Sangre, una conferencia de tres días sobre desórdenes sanguíneos presentada en español. Sesiones educativas y oportunidades para establecer conexiones cubrirán importantes temas de cuidado de la salud, educación y servicios de apoyo. El espacio es limitado.



# WHY I CHOOSE CANNABIS FOR MY PAIN

FELICIA CARBAJAL

*Reprinted with permission.*

*Publication: PEN 2.20*

*Column: As I See It;*

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*www.kelleycom.com*

The cannabis plant has been deeply engrained in American history since our country's inception. Commonly called medical marijuana and hemp, cannabis sativa has been used in everything from textiles and paper to medicines and spiritual tools. Although cannabis has been viewed as harmful or illegal, it has the potential to combat our nation's opioid crisis, repair some of the harm caused by the war on drugs, and offer Americans a natural alternative to pharmaceutical drugs.

Why do I believe so strongly that cannabis can do all of this? It's pretty simple: cannabis has been a wonder drug for treating my chronic pain from a spinal cord injury over a decade ago. It has also revolutionized the treatment of my depression, anxiety, and PTSD, and has numerous therapeutic effects when used in its various forms.

After my last back surgery, a microdiscectomy, I took Vicodin to manage the pain, but this would alter my mood and only mask the pain momentarily. I wasn't myself, and the pain always came back. My medical team said this would be my life. Between the epidural injections and physical therapy sessions, I began researching alternatives.

I tried everything to reduce my pain. I bought gadgets like seat and hand-held massagers, a laser acupuncture pen, and electrostimulation devices. I tried countless complementary therapies like chiropractic treatments and acupuncture. Up to that point, cannabis was last on my list of options. Fortunately, I was

introduced to a world-renowned medical professional who was working with patients on low-dose cannabis options with controlled intake of THC. His team gave me a bottle of tincture to try. Three days later, I was pain-free, no longer needing Vicodin, and smiling.

This introduction marked the beginning of my journey with cannabis. I knew the power of sharing my story, and became even more intrigued by the potential of this plant as I weaned myself off a cocktail of anxiety, depression, and pain meds that caused more harm than good. I knew I had to keep learning.

First, I researched the legal history of cannabis. I grew up a DARE1 evangelist during the 1980s and was unaware of cannabis's history in the US dating back over a century. Hemp was a valuable crop in the American colonies, used for a variety of purposes, including paper and rope. Eventually, it entered American pharmacopeia as cannabis and became a tool for advancing conservative agendas. Today, more than half the country has some form of regulated cannabis, and a majority of states allow the sale and transportation of hemp-derived products.

Next I explored the science of cannabis. I had friends who'd been diagnosed with HIV and AIDS and knew that this was their medicine, but I didn't understand why or how. I dove deep into the research and discovered the endocannabinoid system (ECS).2

The ECS is a network of neurotransmitters and receptors that work round-the-clock to help keep the body in homeostasis. Found throughout the bodies of mammals and other vertebrates, the ECS responds to the presence or deficiency of cannabinoids, which can be endogenous (produced within the

organism) or exogenous (produced externally).

Endocannabinoids are produced internally and regulate the function of just about every physiological system within the body. Phytocannabinoids are endocannabinoids derived from plants, including but not limited to cannabis.

Naturally, I went to my physician and began asking about the ECS. To my surprise, she knew little about it. I shared some links from the National Institutes of Health (NIH)3 and other research bodies4 about current clinical trials and research.

I'm fortunate to live in a state with regulated cannabis, which means I have access to clean, tested cannabis products—a privilege I don't take lightly. I have the opportunity to explore other cannabinoids, including THCA (tetrahydrocannabinolic acid) and THCV (tetrahydrocannabivarin) in conjunction with terpenes, aromatic plant essences found abundantly in cannabis that can provide therapeutic relief and enhance the efficacy of other compounds when combined (the "entourage effect").

For those who are new to cannabis or who live in unregulated areas, take this chance to educate yourself. Check out sites like Project CBD,5 GreenFlower Media,6 and Leafly,7 and dive into the data. Go to the NIH website8 and type "cannabis" along with your condition to review the research. The reality is that cannabis is personalized medicine, and the one-size approach won't work for everyone.

My biggest recommendation: When you explore cannabis, be safe. The cannabis industry is in its infancy; with recent reports of cannabis-induced health concerns, it's imperative to purchase from a licensed, regulated producer. You should

*continued on next page*

# MY BLEEDING DISORDERS COMMUNITY (MYBDC) FOR YOU, BY YOU



For years, researchers studying the bleeding disorders community have sought answers to questions about people's experiences that only community voices can answer.

Your voice is at the center of MyBDC. This community-powered registry will help researchers understand what it really means to live with a bleeding disorder and how current treatments, therapies, and policies affect the community. MyBDC will collect information from the people directly affected: people with bleeding disorders, their parents, siblings, partners, and caregivers.

People who participate in MyBDC will share information consistently over several years through surveys. This will allow researchers to better understand how bleeding disorders affect individuals and their family members across their lifespan. It will also help participants understand their individual situation and how a bleeding disorder affects their life.

The confidential, deidentified aggregate data gathered through MyBDC will ultimately contribute to the goal of improving clinical outcomes and quality of life and identifying research questions important to the community.

MyBDC is open to all people affected by inherited bleeding disorders as well as their immediate family members (parents, spouses, children, siblings, and grandparents).

NHF currently has 543 individuals enrolled of which 312 are affected with an inherited bleeding disorder (IBDs). The MyBDC Personalized Dashboard is now live! You can visit [www.hemophilia.org/Researchers-Healthcare-Providers/MyBDC](http://www.hemophilia.org/Researchers-Healthcare-Providers/MyBDC) to register or for more detailed information on MyBDC.

## WHY I CHOOSE CANNABIS FOR MY PAIN, CONTINUED

be able to view the lab test results of any product you buy, so you know exactly what you're putting in your body. There are lots of options everywhere, including websites like Amazon, so be mindful! And if possible, test what you're using.

Finally, make sure you're aware of the laws and regulations in your area. This is essential as more and more states regulate.

After years of taking opioids, I'm finally free. Cannabis can improve the quality of your life, too. Understand and explore

the possibilities of cannabinoid therapies. Together we can fight the stigma and perception surrounding cannabis, save countless lives from opioid-related overdoses and deaths, and heal the harm from the war on drugs by voting for sensible drug policy.

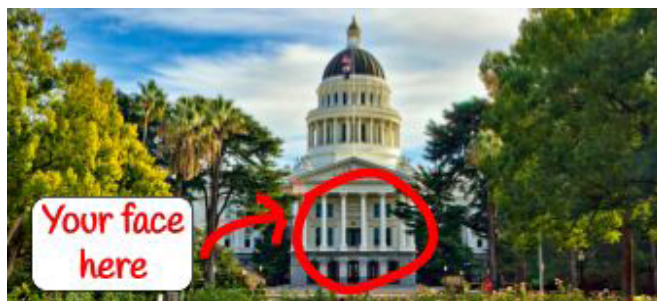
Felicia Carbajal is a values-based community organizer, social entrepreneur, change-maker and innovator in the cannabis industry. Based in Los Angeles, the cannabis capital of the nation, Felicia has over two decades of experience in

California's cannabis market. Felicia has worked with world-renowned cannabis medical professionals, has consulted numerous cannabis brands, and is a trusted resource for multiple patient and consumer communities. Currently Felicia is executive director of the Social Impact Center:  
[felicia@thesocialimpactcenter.org](mailto:felicia@thesocialimpactcenter.org).

1. *Drug Abuse Resistance Education*
2. [www.uclahealth.org/cannabis/human-endocannabinoid-system](http://www.uclahealth.org/cannabis/human-endocannabinoid-system)
3. [nccih.nih.gov/health/marijuana](http://nccih.nih.gov/health/marijuana)
4. [www.cancer.gov/about-cancer/treatment/cam/patient/cannabis-pdq](http://www.cancer.gov/about-cancer/treatment/cam/patient/cannabis-pdq)

5. [www.projectcbd.org](http://www.projectcbd.org)
6. [green-flower.com](http://green-flower.com)
7. [www.leafly.com](http://www.leafly.com)
8. [nih.gov](http://nih.gov)





## Legislative Day 2020: NOW RE-IMAGINED AS A *VIRTUAL* EVENT!!

***Come make your voice heard!  
HCC's Legislative Day 2020 is  
RE-IMAGINED as a VIRTUAL EVENT!!***

Due to the ongoing COVID-19 outbreak, Hemophilia Council of California is ***re-imagining*** the structure of Future Leaders and Legislative Day.

We will **not** be meeting in Sacramento on May 3-5. But in times like these, the voice of the bleeding disorders community; individuals, families and allies, remains as needed as ever at the State Capitol. Please help us to inform our legislators about bleeding disorders and the issues facing our community - not only right now but every day - by participating in our re-imagined VIRTUAL Legislative Day event.

**WHAT:** Legislative Day

**WHEN:** TBD

**WHERE:** ONLINE!!

**WHO:** Individuals affected by bleeding disorders & their families, allies and advocates

**WHY:** You want to advance access to healthcare and quality of life for those affected by bleeding disorders

More information will be forthcoming in the coming weeks, so don't miss a beat-

**Sign up for updates on HCC's now VIRTUAL Legislative Day 2020!**

**<https://bit.ly/HCCvirtualEventUpdates>**

**Questions :** [info@hemophiliaca.org](mailto:info@hemophiliaca.org) or (916) 572-7771

HCC is a statewide nonprofit advancing access to care and quality of life for those affected by bleeding disorders. HCC represents approximately 4,000 individuals with hemophilia, more than 360,000 with Von Willebrand Disease (VWD) and countless others with related disorders.

**Thank you to our Sponsors!**



Jonathan Botelho  
Memorial Advocacy Fund



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[www.hemophiliaca.org](http://www.hemophiliaca.org)

# We're Looking for 2020 Future Leaders! NOW RE-IMAGINED as a *VIRTUAL* Program



**WHAT:** Future Leader Program & Legislative Day

**WHEN:** TBD

**WHERE:** Now a *VIRTUAL* program!

**WHO:** Those affected by bleeding disorders (including carriers and relatives), ages 14-22

**WHY:** You want to advance access to healthcare and quality of life for those affected by bleeding disorders

Due to the ongoing COVID-19 outbreak, Hemophilia Council of California is re-imagining the structure of **Future Leaders and Legislative Day**. We will **not** be meeting in Sacramento on May 3-5. But in times like these, the voice of the bleeding disorders community; individuals, families and allies, remains as needed as ever at the State Capitol. Please help us to inform our legislators about bleeding disorders and the issues facing our community - not only right now but every day - by participating in our re-imagined **VIRTUAL Future Leaders** program. More information will be forthcoming in the coming weeks, so don't miss a beat-

**Sign up for updates on HCC's now *VIRTUAL* Future Leaders Program 2020!**  
**<https://bit.ly/HCCvirtualEventUpdates>**

Hemophilia Council of California's (HCC) **Future Leader Program** provides leadership training and advocacy tools for teens and young adults affected by bleeding disorders. Leading up to HCC's annual Legislative Day, **Future Leaders gain insights on their role in the government process, insurance, programs that support care, educational opportunities, and effective advocacy.**

**How to Apply:** <https://www.hemophiliaca.org/programs/future-leaders-program/>

**Deadline:** Extended

**More details on virtual program coming soon!**

**Questions:** Email [info@hemophiliaca.org](mailto:info@hemophiliaca.org)

## Apply to become a 2020 Future Leader today! More details on new *VIRTUAL* program coming soon!

Thank you to our 2020  
Sponsors!



Jonathan Botelho  
Memorial Advocacy Fund

*We're Listening*



At Pfizer Hemophilia, we have always been deeply committed to you and to listening to what you have to say. Over the years, what you've shared with us has proven invaluable. The events we sponsor, the technology we develop, and the educational materials we create are all designed in response to the requests, needs, and desires of the hemophilia community.

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

—Your Pfizer Hemophilia Team



## 2020

## CALENDAR OF EVENTS

April 16	<b>Virtual COVID-19 Town Hall with Dr. Thornburg and Dr. Von Drygalski</b> VIRTUAL (Zoom Webinar)
April 17	<b>World Hemophilia Day</b>
April	<b>Educational Dinner Program – Sponsored by Medexus</b> VIRTUAL (Zoom Webinar)
May 3-5	<b>Hemophilia Council of California's VIRTUAL Future Leaders Program</b> VIRTUAL
May 5	<b>Hemophilia Council of California's VIRTUAL Legislative Day</b> VIRTUAL
May 25	<b>Memorial Day (Office Closed)</b>
May 29-31 (postponed)	<b>NOW Conference (National Outreach for VWD)</b> Phoenix, AZ
May TBD	<b>Educational Dinner Program – Sponsored by Bayer Healthcare</b>
May 5	<b>#GivingTuesday   NOW</b>
May 30	<b>Golf Clinic &amp; Lunch with Perry Parker</b> Loma Club (Point Loma)
June 15	<b>Educational Dinner Program – Sponsored by Genentech</b> King's Fish House
June 26-29	<b>After the Shock Inhibitor Camp (by CHES)</b> Poconos Foothills of PA
July 3	<b>Independence Day Observed (Office Closed)</b>
July 11-15	<b>Camp Dragonfly (Teen Camp)</b> American River (Lotus, CA)
August 6-8	<b>NHF's 72nd Bleeding Disorders Conference</b> Atlanta, GA
August 8-14	<b>Camp Firefly (20th Anniversary of Camp)</b> YMCA Camp Oakes
August 14	<b>Hemophilia Council of California Health Policy Summit</b> Sacramento, CA
August 24-26	<b>Hemophilia Federation of America Symposium</b> Baltimore, MD
August TBD	<b>Family Education Day</b> Sea World San Diego
September 7	<b>Labor Day (Office Closed)</b>
September 9	<b>Educational Dinner Program – Sponsored by Novo Nordisk</b> TBD
September 18-20	<b>4th Annual Familia de Sangre Conference</b> Anaheim Marriott
October TBD	<b>Educational Dinner Program - Sponsored by Sanofi Genzyme</b> TBD
October 3 (tentative)	<b>Infusion Training with UCSD HTTC and Rady's HTTC</b> Mesa Rim (Mira Mesa)
October 25	<b>8th Annual Unite for Bleeding Disorders Walk</b> Liberty Station Park
November 11	<b>Veteran's Day (Office Closed)</b>
November 12	<b>Educational Dinner Program – Sponsored by Spark Therapeutics</b> TBD
November 20-22	<b>NHF Inhibitor Education Summit</b> Denver, CO
November 21	<b>Imperial Education Day</b> TBD
November 26/27	<b>Thanksgiving (Office Closed)</b>
December	<b>Educational Dinner Program – Sponsored by Takeda</b> TBD
December 1	<b>#GivingTuesday</b>
December 13	<b>Factor &amp; Frost</b> Westin San Diego Gaslamp
December 24-31	<b>Holidays (Office Closed)</b>



**Hemophilia Association of San Diego County**

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