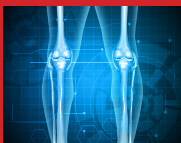


LETTER FROM THE PRESIDENT THE YEAR AHEAD



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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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FROM THE PRESIDENT

SEAN PENTZ
HASDC
BOARD PRESIDENT

First, I would like to thank the Board of Directors of the Hemophilia Association of San Diego County and the community for allowing me to continue to serve as Board President and be part of such a great organization. HASDC was formed in 1954 by a small group of individuals who were looking for better treatment options, better access to care, educating others about living with a bleeding disorder and advocating on behalf of those with bleeding disorders. I intend to keep that mission alive.



The next year is going to be a challenge as we, along with the rest of the world, continue to face the side effects brought on by the pandemic. All of our educational events have had to move to digital platforms, which has drastically affected our budget, ability to hold events and raise funds. Nooshin, the board of directors, and our stakeholders are working tirelessly to expand our capacity to provide meaningful educational experiences through digital means. In order to be able to do a better job we need to hear from you! So, pay attention to your social media, email and mail as more information about our need's assessment will be announced soon.

Another challenge we face is increasing our community participation. As a community-based organization, we're always faced with the task of bringing in new community members as others leave. This can be especially difficult given the pandemic, but the board and I are committed to continue to strive to reach more of the community with educational programming. We look forward to partnering with our local stakeholders to better connect with individuals and families affected by bleeding disorders.

Despite the past year, there is a lot of positive change on the horizon too. There are novel therapies currently under investigation that could drastically change the lives of those with bleeding disorders. Whether it's gene therapy or other novel therapies, I believe there is much to be hopeful for in regards to future treatment options. It will be up to us to continue to work together so that we can continue to fight for access.

For those currently living in San Diego or Imperial Counties I want to assure you that my intention, and that of the board of directors, is to grow, engage, educate and advocate for that caregiving for or living with a bleeding disorder. I look forward to a productive year of change and want to encourage each one of you to participate and become more involved.

Best Regards,

Sean

Sean Pentz
Board President

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."



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



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KEEP YOUR LOWER EXTREMITY JOINTS MOVING!



The pandemic impacted everyone's life in 2020, making it especially hard to stay healthy. While many of us began exercising from home, some of us have completely stopped exercising because of the increased stress of working from home, managing our children's school schedules, gyms closing, expensive home exercise equipment, or just being out of routine.

This isn't good for anyone, but if you have a bleeding disorder, lack of exercise can cause major setbacks, including joint stiffening, that put you at greater risk of joint bleeds and more joint damage.

As a physical therapist with severe hemophilia, I'm going to focus on eight imperative workouts to perform daily without any equipment at all. And I'll explain why these are important to maintain strength and reduce areas of common joint damage!

1. SIT TO STAND

Sit in a chair, cross your arms, keep feet shoulder-width apart, toes pointed forward, and stand up. Slowly lower yourself into the chair, repeating 9 more times for a total of 10. If this is challenging, use your arms for support until your legs build strength. If this is easy, find a lower surface. Purpose: Build strength through the quads and glutes to reduce difficulty with walking and stair negotiation, while reducing pressure on the knee and hip joints.

2. GLUTE BRIDGES

Lie on your back, making sure your spine is neutral. Bend both knees, keeping your feet on the floor. With your knees slightly apart, push through your heels to raise the hips up. If this is challenging, use your arms to help push your body up. If this is easy, progress to perform one leg at a time. Purpose: Build strength through the glutes and the hamstrings. Also great for core activation and balance if performing with one leg. Building up sufficient glute and hamstring strength will also reduce pressure on the knee and hip joints.

3. STANDING HIP ABDUCTION

Stand facing a wall, with hands on the wall, knees shoulder-width apart. Start with one leg. Slowly bring it out to the side with toes pointing forward, and then return. Begin with 10–12 repetitions (reps) and progress to 15–20, making sure your body is not rocking sideways. If this is easy, progress to doing the reps without holding onto the wall. While performing this on the right side, the left side is focused on stabilizing, so both hips will feel the workout! Purpose: Build strength in the gluteus medius, which will keep you upright when walking and improve overall balance to reduce your risk of falling.

4. STANDING HIP EXTENSION

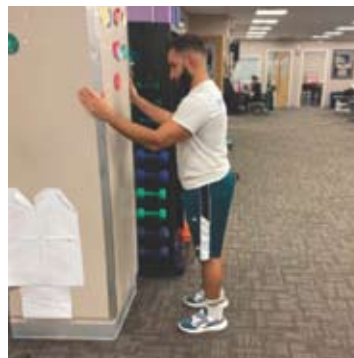
Stand facing a wall, with hands on the wall, knees shoulder-width apart. Start with one leg, and slowly extend the leg back, with toes pointing forward. Make sure the lower back is not arching backward or forward; squeeze the glute to engage proper activation. Begin with 10–12 repetitions (reps) and progress to 15–20, making sure your body is not rocking sideways. If this is easy, progress to not holding onto the wall. Purpose: Build endurance to reduce difficulty in activities requiring prolonged periods, such as hiking or taking long walks. Improving glute strength and performing standing extension-based exercise is important because we are often in the flexed posture throughout the day.

5. PENGUINS

Stand with your toes pointing forward, and waddle side to side, standing in place. You'll feel this in the sides of both hips. Begin for 10–20 seconds with feet 1 to 2 inches apart, and progress to 30–60 seconds with feet 3 to 5 inches apart. Purpose: Build further gluteus medius strength and improve balance. While you balance on the one lower extremity, the other is working. Balance training has been shown to reduce pain in the ankle and knee, and reduce effects of osteoarthritis.

6. HEEL RAISES

Stand facing a wall, with hands on the wall, toes pointed forward. Slowly raise your body up on tiptoes. Progress to not holding onto the wall, and further progress by standing on toes using both feet going up, and then lowering down on one. Start with 10–15 reps, and progress to 20–30 reps. Purpose: Build strength through the calves, to improve strength during walking. Ankle bleeds are common, but ankle muscles are not commonly exercised. Having strong ankles will reduce strain that moves up through the knee, hip, and lower back.



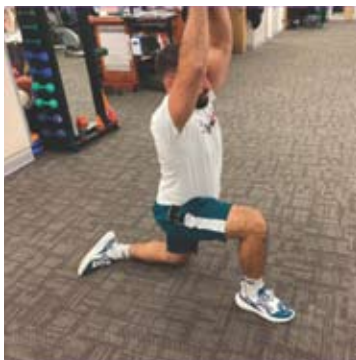
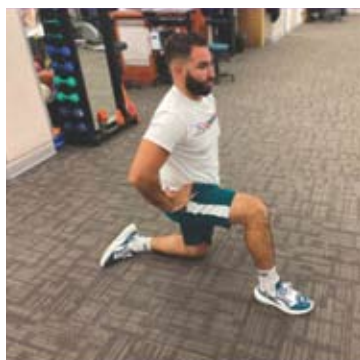
7. HIP FLEXOR STRETCH

Kneel on one knee, with the other at a 90-degree angle in front of you. Maintain upright posture, and keep your sternum/chest bone pointing upward. Slowly lean forward and feel the stretch through

the groin. Begin by holding 15–20 seconds if you're under age 65, and holding 30–60 seconds if you're over 65, to help stretch the collagen. Progress by engaging the glutes to feel an increased stretch through the iliopsoas. Purpose: Reduce strain on the quad and low back by improving mobility and flexibility of the hip flexor. Since most people are in a flexed posture and seated position for long periods, the iliopsoas tends to get super tight and is an area of increased muscle bleeds. Maintaining good range of motion will reduce the chance of target joints.

8. HAMSTRING STRETCH

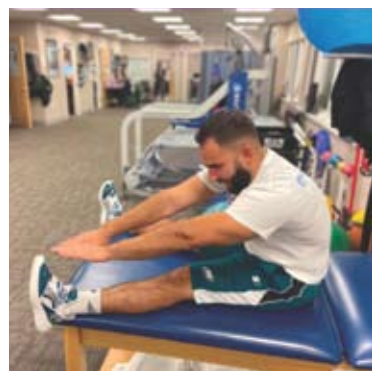
In a seated position, have your legs apart, and slowly lean toward one ankle. Begin by holding 15–20 seconds if you're under age 65, and 30–60 seconds if you're over 65 to stretch the muscle. Progress by reaching farther to improve the stretch. Purpose: Reduce strain on the low back and knee joints by improving the mobility and flexibility of the hamstrings. If you spend a lot of time in a flexed posture and seated position, the hamstrings tend to get super tight. Maintaining good range of motion will reduce the chance of developing target joints.



A pandemic can make working out a challenge. These eight simple exercises focus on mobility, balance, and stability, and target all the major muscle groups. They can be performed at home without any equipment. I highly recommend performing these exercises daily, and after six to eight weeks, you'll see a major improvement. Exercise is vital if you have a bleeding disorder. The time to start is NOW!

Michael Zolotnitsky, PT, DPT, is director of neurological rehabilitation at New Jersey Spine and Wellness in Old Bridge, New Jersey. He also has severe hemophilia A. He can be reached at 732-952-2292 and michael.zolotnisky@spineandwellness.com.

Article from PEN 2.21.



BOARD CORNER

MEET TREVOR MESSERLY

Did you know Trevor is our Youth Board Member? We asked him a few questions so you could get to know him.



WHAT MAKES OUR ORGANIZATION'S MISSION POWERFUL FOR YOU?

The mission of supporting the bleeding disorders community is a passion of mine because we are stronger together.

WHAT INTERESTS YOU MOST ABOUT OUR ORGANIZATION?

I'm very interested in the two camps offered. I think having a place to hang out in an active way with people going through similar things, but in an environment purely revolved around bleeding disorders. Being able to see another person climb a rock way or go ziplining with a bleeding disorder really helps myself to not be limited by my Hemophilia.

DO YOU HAVE PERSONAL ASPIRATIONS ABOUT SERVING ON OUR BOARD?

Whether I am in a four-year university or community college I would be very interested in serving my community through the board of the Hemophilia Association of San Diego County.

WHAT DOES SUCCESS LOOK LIKE TO YOU?

Success to me is not measured by a standard rubric. It is really up to your own perspective on whether you achieved what you wanted to achieve and if you gave your full effort towards your goals. I do not think you should feel down if you didn't achieve others expectation of success. No one knows you like you know yourself, what you're capable of and what you wish to achieve.

WHAT MOTIVATES YOU?

What motivates me is my family. Seeing my mom being one of the hardest working people I know motivates me every day when I wake up. My siblings all having success whether academically or professionally motivates me to try to have similar success. I have my own dog, I pay for all the expenses, which motivates me to have a job. I can save for college and provide him good food, a good vet, and some nice toys.

IS THERE ANYTHING ELSE YOU WOULD LIKE TO SHARE WITH THE COMMUNITY?

I would like to share with other people to be involved in the community. Go to events and become friends with people in the community. We have a very strong bleeding disorder community here in San Diego. Becoming involved can help you in so many different ways. Whether it is bleeding disorder related or not. Knowing there are other people going through similar struggles will give you more strength and support to get through things.

UC SAN DIEGO
HEALTH
HEMOPHILIA
& THROMBOSIS
TREATMENT
CENTER

UC San Diego Health

WOMEN WITH BLEEDING DISORDERS PROGRAM

UC San Diego's Hemophilia & Thrombosis Treatment Center has recently introduced the Women with Bleeding Disorders Program. This new clinic is a collaboration between UCSD Hematologists and Gynecologists and is currently held one Friday of each month through virtual/tele-health visits. The focus of the program is to provide multidisciplinary management and evaluation for females with bleeding disorders who experience heavy menstrual bleeding, which is an underrepresented population.

If you would like more information, or to make an appointment, please call the Hemophilia & Thrombosis Treatment Center 858-657-6028

RADY
CHILDREN'S
HOSPITAL
HEMOPHILIA
& THROMBOSIS
TREATMENT
CENTER

WOMEN AND GIRLS HEMATOLOGY/GYNECOLOGY CLINIC



WOMEN AND GIRLS HEMATOLOGY & GYNECOLOGY CLINIC

Dr. Ding has developed a NEW Women and Girls specialty clinic which is especially designed for teens with heavy menstrual bleeding. This clinic is in collaboration with Dr. Irene Su, a gynecologist at UC San Diego. The clinic is held on Friday afternoons at Rady Children's Hospital San Diego. Please contact the HTC for more information. 8858-966-8163.

MEET DR. BUSH

Bush is a new doctor in the Hemophilia and Thrombosis Treatment Center who will work with Dr. Thornburg and Dr. Ding. She recently completed a specialized training program in bleeding and clotting disorders at Rady Children's Hospital San Diego under the mentorship of Dr. Thornburg. She is especially interested in improving the quality of care for individuals with blood disorders.

INFUSION TRAINING

The HTC team created a new infusion video. Scan the QR code to view.



Rady
Children's
Hospital
San Diego

WHAT DO PATIENTS NEED TO KNOW ABOUT MEDI-CAL RX

LYNNE KINST
EXECUTIVE DIRECTOR,
HEMOPHILIA COUNCIL
OF CALIFORNIA

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.





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

A PASSION FOR MUSIC: THE CURRENCE BROTHERS



Have you heard of the Currence Brothers? This band from West Virginia played and recorded gospel, bluegrass, and country music in the 1970s. The band members were known for their musical talent, especially with the banjo and fiddle. And two Currence brothers, plus their nephew, happened to have hemophilia. These band members overcame hardships to fulfill their passion for music.

For five generations, the musically inclined Currence family lived in High Germany on the Randolph-Upshure county line in central West Virginia. They lived in a six-room house on a small farm, four miles from a paved road. The nearby one-room school in High Germany housed 45 students in eight grades.

Every member of the large Currence family—including seven boys and five girls—either played a musical instrument or sang, though none was trained or ever had a music lesson. The children and their parents would listen to a battery-powered radio or hear live entertainment, then pick out the tune on guitar, fiddle, or mandolin. At home or in church, the family members sang and played musical instruments.

There appeared to be no family history of hemophilia. That is, until one of the Currence boys, Junior (1923–1925), died at age two after he bled out from a bumped nose, and hemophilia was later suspected. Junior's younger brothers Jimmie (1932–1992) and Loren (1934–1987) grew up with bleeding issues, but they never visited a doctor until they were teens. There was no ice for treatment and nothing for pain, though the reason for this is unclear. The brothers applied high-powered liniments from Blair products for hemorrhages into their joints.

Jimmie and Loren seem to have visited at least one local doctor, and they were treated as “bleeders.” It's possible that lack of money, transportation, and awareness of the need for a hematologist may have prevented visits to an appropriate specialist or hematology lab. Before factor VIII factor concentrates became available, the brothers received blood transfusions. Loren once received sixteen pints of blood for a kidney bleed. When Jimmie had a stomach bleed as a teenager, he received a pint of blood from his brother-in-law. The boys were often laid up from hemorrhages into their joints or from other internal bleeds.

Jimmie and Loren didn't have their hemophilia diagnosed until the early 1960s. Dr. Mabel M. Stevenson, a hematologist at Morgantown University Hospital, diagnosed severe classical hemophilia in both brothers, who then called themselves “severe hemophiliac bleeders with near-zero clotting factor.” Neither brother could ever find full-time employment or get insurance. They both received supplemental social security, and the state of West Virginia paid for their medicine because they couldn't afford it. Both brothers married, and each had three daughters.

Brothers Jimmie, Loren, Marvin (“Shorty”), and Buddy—along with Malcomb Pastine, a nephew who also had hemophilia—formed the

Currence Brothers Band. Loren played guitar, sang, and managed the band. Jimmie played fiddle and banjo, winning banjo and fiddle contests in four states: West Virginia, Maryland, Pennsylvania, and Virginia. Jimmie won the fiddling championship in West Virginia for four consecutive years, and was undefeated grand champion in Maryland in 1970. Then his elbow bleeds forced him to switch from fiddle to banjo. Malcomb played guitar, and even did turkey calls. Buddy sang, while Marvin played the fiddle.

The Currence Brothers began spreading the gospel by playing their music at church functions. They traveled the country, usually in their van, to play in concerts and on radio or television. The band even recorded on their own, or with notable musicians, producing several albums in a genre they called Gospel Grass, along with a mixture of popular tunes. They collaborated with musicians including Larry Groce, who they met at a talent show at the firehouse in Parsons, West Virginia; Woody Simmons, who lived in Randolph County; Clyde See; and “Country” Charlie Jordan.

You can find Currence Brothers music on old vinyl records and in a few YouTube videos. Check out the following albums:

- The Currence Family, *Precious Memories* (Lark Records, n.d.)
- Larry Groce and the Currence Brothers (Peaceable Records, 1975)
- Larry Groce, *Junkfood Junkie* (Warner Bros. Records, 1976)
- The Currence Brothers, *He's Coming Back to Earth Again* (Major Recording Studios, n.d.)
- The Currence Brothers Sing and Play Gospel Grass (Major Recording Studios, n.d.)
- The Currence Brothers, *Ballads and Instrumentals* (Major Recording Studios, 1978)
- The Currence Brothers, *Muddy Boggy Banjo Man* (Major Recording Studios, 1979)
- Woody Simmons, *All Smiles Tonight* (Elderberry Records, 1979)
- The Currence Brothers, *That's the Man I'm Looking For* (Augusta Records, 1981)
- Clyde See with the Currence Brothers (Augusta Records, 1983)

The Currence Brothers are known for their talent on the banjo and fiddle, not for having band members with hemophilia. Their hemophilia did not define them, and it never prevented them from making music. Of course, some accommodations were made—switching instruments due to elbow bleeds; not playing at some events or traveling as much as they wanted—but not at the expense of their artistry and passion. Today, other family members continue the Currence musical tradition.

To learn more, read profiles of the Currence Brothers and other West Virginia musicians in *Mountains of Music* (University of Illinois Press, 1999), edited by John Lilly.

Article from PEN 2.21

WELLNESS CORNER

BY SEAN PENTZ
BOARD PRESIDENT

BEING MINDFUL OF OUR HEALTH

For thousands of years Buddhist tradition has practiced the art of meditation to better understand themselves and their connection to the world. In doing this they hope to be released from pain and to ultimately reach enlightenment.

In recent years, scientists have gained insight to the benefits of this ancient practice. Studying the effects of secular versions of mindfulness meditation, they've found that listening to our current experiences and coming to accept them can lead us to feel happier. Studies suggest that there can be a lot of positive effects from meditation such as, improving our mood, decreases in anxiety, and increases job satisfaction.

Beyond the help mindfulness has on one's psyche, scientists have been looking at whether or not meditation can also help people's bodies. In the past many scientists relied on pilot studies with limited participants and biased measures, but recently scientists have been introducing less-biased physiological measures and controlled grouping to gain better insight into the effects of meditation on the body. Although no evidence suggests that meditation and mindfulness alone can be a treatment for disease there is a growing body of evidence that shows many of their benefits.

Heart disease has been the number one killer in the United States over the past century killing 1 in 4 Americans each year. So, any treatment or activity that could help reduce this number could leave a huge impact on society. Mindfulness can perhaps help. In one study, individuals with pre-hypertension were split into two groups with one receiving a course on mindfulness meditation and the other group was taught progressive muscle relaxation. The group that practiced mindfulness meditation had significantly greater reduction in systolic and diastolic blood pressure when compared to the group that practiced progressive muscle relaxation. This is of significant importance to those with bleeding disorders as there's a strong correlation between use of recombinant factor 8 products and an increase in blood pressure, which over long periods of time can lead to heart disease amongst many patients. In another study, patients with heart disease were placed into a group that was able to receive a program to practice mindfulness and another group got waitlisted for the program and just continued normal treatment for heart disease. Individuals who took the mindfulness program showed significant

improvements on the six-minute walking test (a measure of cardiovascular capacity) and lower heart rates than the group that was waitlisted. Now these are just some preliminary studies and the results are mixed, but in a more recent review by the American Heart Association found that there is enough evidence to suggest that mindfulness as an adjunct treatment for coronary heart disease and its prevention.

As one ages, they tend to lose some of their cognitive flexibility and short-term memory. But mindfulness could perhaps help stunt cognitive decline, even in people with Alzheimer's. A 2016 study found that when people with Alzheimer's practiced mindfulness meditation they had much more robust cognitive scores than those who used cognitive stimulation therapy, relaxation training or no training. While this data is still preliminary a systematic review of research to date published in *Annals of The New York Academy of Sciences* shows that mindfulness may mitigate cognitive decline, possibly because of its effects on memory, attention, processing, and executive function.

These are just a couple of the newly discovered benefits of practicing mindfulness. Incorporating mindfulness in my life has helped me personally as I strive to deal with physical and emotional pain from dealing with my bleeding disorder and hopefully it can help you too. Here are a couple resources to help you get started on practicing mindfulness:

Resources

Website: Mindful.org is a great place to start your journey on practicing mindfulness. Simply click on the 'Get Started' tab to begin your path to improving your health!

Book: "The Headspace Guide to Meditation and Mindfulness: How Mindfulness Can Change Your Life in Ten Minutes a Day," by Andy Puttycombe, the founder of the Headspace App, and a former Buddhist monk with a ton of experience teaching the practice of mindfulness. He began his career like so many of us - a normal guy who's constantly busy with work and stressed out. He does an amazing job weaving practices of mindfulness into stories drawn from his own life experience that allow the reader to better understand just how impactful 10-minutes of meditation a day can be!



**WELLNESS
(WEL-NIS):
THE QUALITY OR
STATE OF BEING
HEALTHY IN BODY
AND MIND, AS
THE RESULT OF
A DELIBERATE
EFFORT.**

EULOGY BY SEAN PENTZ
HASDC BOARD PRESIDENT

IN MEMORY OF YVETTE BRYANT

A LEGACY OF ADVOCACY, PASSION, & HUMOR



It is with deep sadness to inform the community that in 2020 we lost the wonderful Yvette Bryant, former HASDC Board President. She leaves behind her husband Tommy, three wonderful children Victoria, Mike and Matt, and a legacy of advocacy.

Her passion for the community grew out of the love she had for her son Matt who was diagnosed at a young age with Hemophilia. She tirelessly worked for access to care for well over a decade on both the board of directors of the Hemophilia Association of San Diego County and the Hemophilia Council of California. With a booming voice and infectious smile her presence at board meetings and events was undeniable.

Personally, I remember Yvette as the most supportive person on the Board of Directors. When I joined over a decade ago at only 24 years old, she went out of her way to explain the ins and outs of being a board member and all that entailed. Whether it was explaining some of the bylaws or making me chuckle discussing music, her presence always made me smile. Her children continue her legacy each in their own way, with her daughter Victoria even becoming our Camp Director at Camp Firefly.

Thank you, Yvette, for your years of service to the bleeding disorders community you will be greatly missed!

WORDS FROM THE COMMUNITY

To the Bryant Family:

My name is Robert Friedman and I want to express my heartfelt condolences to you all. Today and always, may the loving memories of Yvette bring you peace, comfort and strength.

I recall Yvette spoking often of her Family and she was so proud of you all! Always smiling, laughing and loving life and being a proud Mom indeed.

I have known Yvette since 2009 and mostly through the numerous wonderful California Coastal Rides for Hemophilia that we participated in together. Yvette made all of the CA Coastal Rides truly amazing journeys of fun, laughter, fundraising, friendship and truly something special and unique for the bleeding disorders community in California. Watching Yvette laugh, smile and joke with everyone throughout these events is a lasting memory I will always have. She truly "was" almost the event itself as so much of her personality and love of community went into these events and we as participants always truly felt that.

It was impressive to see Yvette always working so hard to put together great programs and events for the community that she was so dedicated too. I recall Yvette working long hours cooking up great pasta dinners, creating breakfast buffets and lunches for all the hungry bike riders and individuals supporting each annual ride. She wanted these Coastal Rides to be perfect, safe, and important because that was her caring personality that shone so bright.

Yvette, you are greatly missed and thank you for being such a wonderful person and making this world a better place.

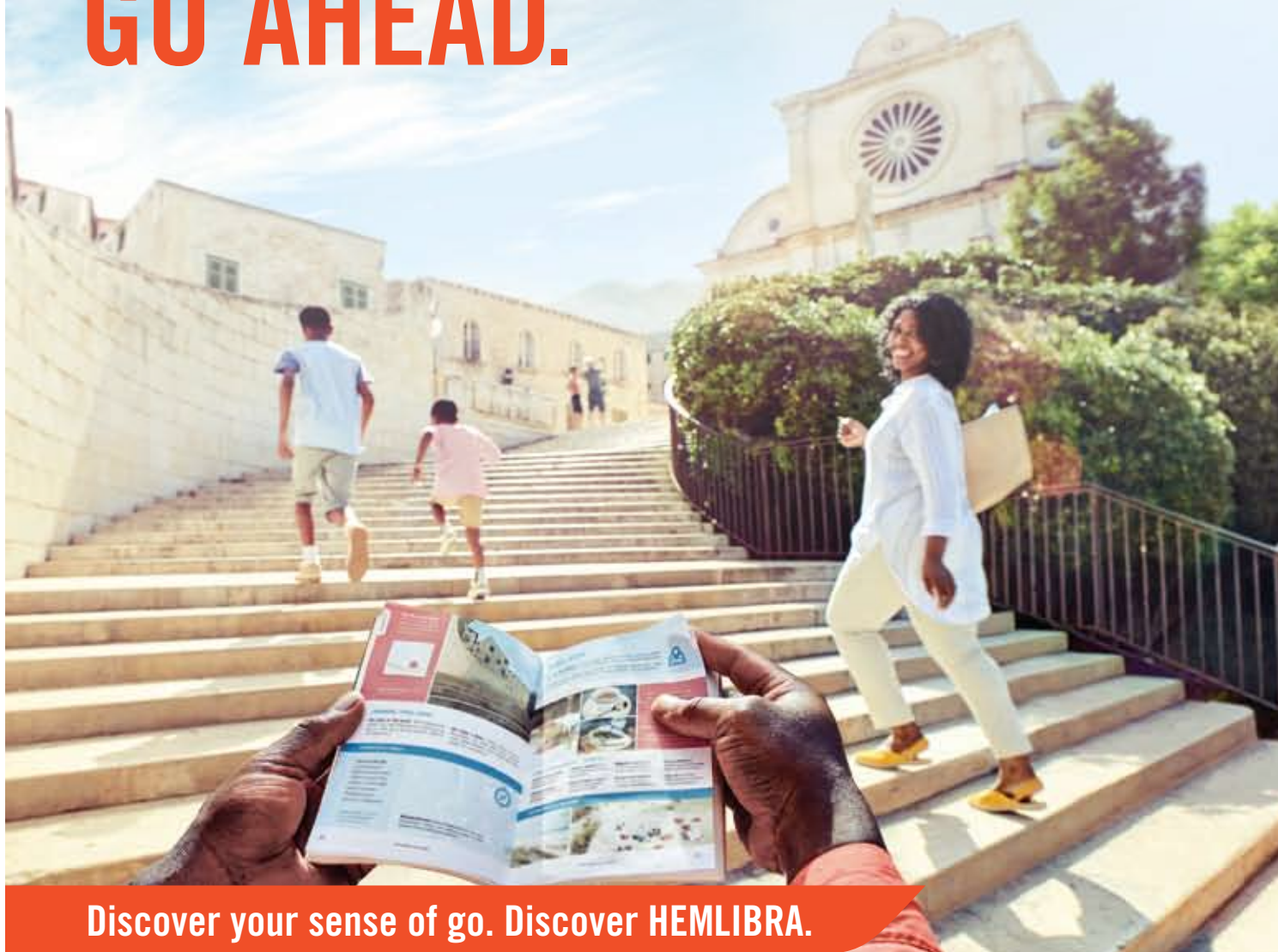
With much respect, appreciation and gratitude.

Robert Friedman



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**.



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 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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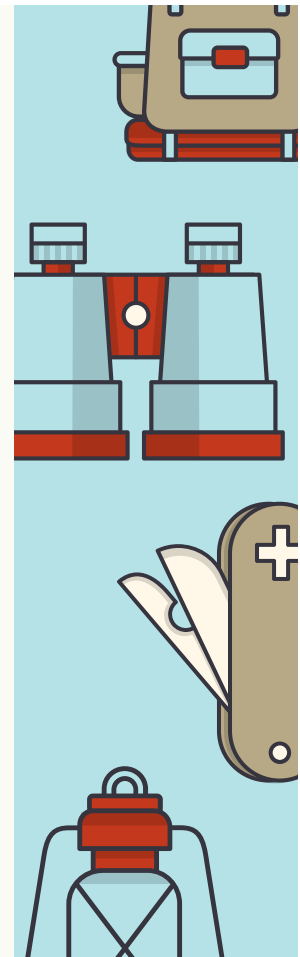
SAVE-THE-DATE

CAMP DRAGONFLY

AUGUST 2-4, 2021

TO BE HELD VIRTUALLY IN PARTNERSHIP WITH GUTMONKEY

WWW.HASDC.ORG/CAMPDRAGONFLY



SAVE-THE-DATE

FAMILY EDUCATION DAY

MAY 1, 2021

TO BE HELD VIRTUALLY OVER ZOOM

WWW.HASDC.ORG/EVENTS



2021 CALENDAR OF EVENTS

DATES SUBJECT TO CHANGE | ALL EVENTS ARE CURRENTLY VIRTUAL

JANUARY

1 | New Year's Day (Office Closed)

FEBRUARY

27 | Advocacy Forum

16 | Educational Dinner Program

MARCH

1 | Bleeding Disorders Awareness Month

11 | Educational Dinner Program

25 | Educational Dinner Program

APRIL

10-16 | The Amazing Goosechase

17 | World Hemophilia Day

14 & 21 | Educational Dinner Programs

MAY

1 | Family Education Day

20 | Educational Dinner Program

JUNE

9, 16, & 23 | Women's Retreat

30 | Wellness Wednesday Summer Series

JULY

TBD | Camp Firefly (youth camp)

13 | Educational Dinner Program

AUGUST

2-4 | Camp Dragonfly (teen camp)

21 | Industry & Back to School Symposium

SEPTEMBER

17-19 | Familia de Sangre Conference

30 | Educational Dinner Program

OCTOBER

23 | Unite for Bleeding Disorders Walk

TBD | Educational Dinner Program

NOVEMBER

TBD | Educational Dinner Program

DECEMBER

12 | Factor & Frost

TBD | Educational Dinner Program

23-31 | Holidays (Office Closed)

TO REGISTER FOR A PROGRAM VISIT:
WWW.HASDC.ORG



Hemophilia Association of San Diego County

3550 Camino Del Rio North, Suite 105

San Diego, California 92108

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