Infusions

WINTER 2020

IN MEMORIAM

Sarah

Sarah at The Female Factor Retreat.

Sarah at HFNC office.

Written by Barbara Forss

Sarah Chan. From the moment I met her, there was something really special about her. I couldn't really define it, but she was just so...cool. With everything going wrong in her life, health-wise, financially and emotionally. I actually envied her "matter-of-fact" take on being a severe bleeder. She was that cool. And funny! So funny. Always wise-cracking with that peculiar kind of dark humor those of us who live with chronic conditions laugh at.

Maybe it's because I struggled to have kids, and because of my undiagnosed FVIId, then finally had to have a total hysterectomy at age 29, childless. Maybe it was her very dry wit and self-effacing humor. Maybe it was her need to advocate for the GT Community. Or, for Women With Bleeding Disorders. Maybe it was all of the above. Sarah, for just the short time that I knew her, became my Daughter-From-Another-Mother.

I do know that after meeting Sarah for the first time, I just embraced her. She was so much fun to be around! Never did

Continued on Page 2

Ziggy

Ziggy in action.

Ziggy at DAO.

Written by Ben Martin

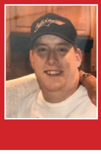
On Nov. 9, the bleeding disorder community lost one of our strongest allies when Donald "Ziggy" Douglas passed away unexpectedly at his home in Hawaii.

Before he took over as Executive Director of the Hawaii Chapter of the National Hemophilia Foundation a few years ago, he had been based out of Southern California and working in the bleeding disorders industry since 2004. Though he didn't have any personal ties to the community, he dove in head first and touched countless lives over the years.

Ziggy attended Camp Hemotion as a counselor for many years and was instrumental in establishing HFNC's B-Leaders program, served as co-director of Family Camp and played a key role in keeping Disabled Adventure Outfitters up and running during a time when the organization was at risk of folding. He was also a long-time volunteer for the Hemophilia Council of California, where he helped run the Future Leaders program in addition to serving as secretary on the Board of Directors.

Continued on Page 2

IN THIS ISSUE



NEWSLETTER OF THE HEMOPHILIA FOUNDATION OF NORTHERN CALIFORNIA

SARAH *Continued from Page 1*

I hear her complain, even when she was at her worst and deserved to. In the short time I knew her, she lost both of her parents. That "Mother" in me wanted to just hold and hug her forever, and let her know that we, the Bleeding Disorders Community, would be there for her any way we could. And you know what? We were! She inspired that in all who she met.

It was traumatic for many of us when we found out that Sarah lost her life-long, 28-year battle with Glansmann's Thrombasthenia, GT. She fought her hardest to live, and that funny side of her was still joking into the last few weeks of her life. When she had two slight falls a few days apart, that caused some major bleeding, I told her I wanted to duct tape her to the wall to keep her safe. She replied, "Only if it's next to the refrigerator!" Sarah, my Foodie Friend! Little did I know the meals we shared in Anaheim would be our last. In fact, our last messages to each other were about the trip she planned to visit me here in the Pacific NW, and figuring out where we could find the best Asian bistros!

But I choose to celebrate our short time together, and remember Sarah for her brains, charm, advocacy and inner beauty. God puts people into your life for a reason, and I think in my case with Sarah, it was to learn humility, patience and perseverance. Something she taught me. Our Community was blessed to have her, and I can see her smiling eyes and button nose now, giggling as we think of her, in her very own "Aw, shucks!" way. We love you Sarah, and we celebrate you!

Sarah painting at The Female Factor Retreat.

ZIGGY *Continued from Page 1*

On a national level, he ran many a teen program for both the National Hemophilia Foundation and the Hemophilia Federation of America, spreading his enthusiasm and energy across the country. As part of the planning committee for NACCHO, his influence extended to camp directors who attended from all over the world.

Since moving to Hawaii, he worked tirelessly to earn the trust of the local community on the islands and had made great strides in strengthening the Hawaii

Every summer you could find Ziggy at summer camps all over the country, bringing energy and enthusiasm everywhere he went. At camp, his booming voice carried many a campfire, his elaborate costumes and games brought every theme imaginable to life. On rafting trips, he inspired teens by running the biggest rapids on a kayak by day and taught them camping skills by night.

He loved camp so much that he invited his oldest daughter, Tierra, to attend Camp Hemotion as well once she was old enough to be on staff, a role she filled for several years. When he wasn't in the middle of one teen program or another, he could be found attending softball games to watch his other daughter, Aubrey, no matter where she was in the country.

It's no secret that it takes a lot for those without family ties to bleeding disorders to become a part of our community, and so I can think of no higher compliment than to say he was loved like a brother by so many of us, as evidenced by the outpouring of love and sympathy following his passing. He was always aware that he was, at least to some degree, on the outside looking in, but that never stopped him from giving everything he had to the work he was doing, and it was evident how much it touched him when he was made to feel like a part of our family.

Ziggy will be missed by many, and his influence will live on forever through the work that he did.

Ziggy at Bleaders.

MARCH IS BLEEDING DISORDERS AWARENESS MONTH

You can ask your mayor to declare your city.
It's easy, an email request starts the process.
Contact ashley.gregory@hemofoundation.org to get started!

LEGISLATIVE RESOLUTION COMMEMORATING MARCH AS BLEEDING DISORDERS AWARENESS MONTH

WHEREAS, THE MAYOR OF YOUR CITY CALIFORNIA IS PROUD TO COMMEMORATE MARCH 2021 AS BLEEDING DISORDERS AWARENESS MONTH IN THE CITY OF ______; AND

WHEREAS, THIS DESIGNATION WILL FORMALIZE AND EXPAND UPON THE DESIGNATION 35 YEARS AGO OF MARCH 1986 AS "HEMOPHILIA AWARENESS MONTH" BY PRESIDENT RONALD REAGAN; AND

WHEREAS, THE FEDERAL DEPARTMENT OF HEALTH AND HUMAN SERVICES DESIGNATED MARCH 2016 AS NATIONAL BLEEDING DISORDERS MONTH; AND

WHEREAS, THESE BLEEDING DISORDERS, WHICH SHARE THE INABILITY TO FORM A PROPER BLOOD CLOT, ARE CHARACTERIZED BY EXTENDED BLEEDING AFTER INJURY, SURGERY, TRAUMA OR MENSTRUATION AND CAN LEAD TO SIGNIFICANT MORBIDITY AND CAN BE FATAL IF NOT TREATED EFFECTIVELY; AND

WHEREAS, MANY INDIVIDUALS WITH HEMOPHILIA BECAME INFECTED WITH HIV AND HEPATITIS C IN THE 1980S DUE TO THE CONTAMINATION OF THE BLOOD SUPPLY AND BLOOD PRODUCTS; AND

WHEREAS, THIS AWARENESS MONTH WILL GENERATE GREATER AWARENESS AND UNDERSTANDING OF NOT ONLY HEMOPHILIA BUT ALL INHERITABLE BLEEDING DISORDERS, INCLUDING VON WILLEBRAND DISEASE—WHICH ALONE IMPACTS AN ESTIMATED ONE PERCENT OF THE U.S. POPULATION OR MORE THAN 3.2 MILLION INDIVIDUALS; AN ESTIMATED 7,158 INDIVIDUALS IN _____AND

WHEREAS, THIS AWARENESS MONTH WILL FOSTER A GREATER SENSE OF COMMUNITY AND SHARED PURPOSE AMONG INDIVIDUALS WITH ALL INHERITABLE BLEEDING DISORDERS; AND

WHEREAS, THIS AWARENESS MONTH WILL ELEVATE AWARENESS OF, DIAGNOSIS AND TREATMENT OF, AND ENGAGEMENT IN THE INHERITABLE BLEEDING DISORDERS JOURNEY BEYOND OUR COMMUNITY TO THE GENERAL PUBLIC, ENABLING THE PREVENTION OF ILLNESS, UNNECESSARY PROCEDURES, AND DISABILITY; NOW, THEREFORE BE IT RESOLVED, THAT THIS MAYOR'S OFFICE OF ______CALIFORNIA PAUSE IN ITS DELIBERATIONS TO PROUDLY COMMEMORATE MARCH AS BLEEDING DISORDERS AWARENESS MONTH IN THE CITY OF _______IN THE STATE OF CALIFORNIA.

AWARDS

Above and Beyond Award Winner Connie Mendoza

Written by Connie Mendoza

My family.

Hello, my name is Connie Mendoza. I am a mother of 3 children, one of which has hemophilia. My father had hemophilia and died when I was 2 years old. My mother did not tell us about my father's hemophilia as we were growing up. Therefore, I did not know I was a carrier. It was not until one of my nephews was born and was diagnosed with hemophilia that my sisters and I started looking for information. I live in Modesto and my sisters live a distance away from me in Los Angeles. Because of the distance not all information was shared between us. Three years passed when I had my second little boy. It was when he was 2 months old that he was diagnosed with hemophilia. From that day my husband and I began to look for information on how to learn about hemophilia.

It was then that we became part of HFNC. As time went by, I became more involved in the events that the foundation organized. It is because of my involvement that I have learned what I know today about hemophilia. I enjoy attending events because I have the chance to talk with other families and learn more about bleeding disorders.

The reason I volunteer at HFNC is because I want to help other families who are going through the same situation that me and my family went through when we found out that my son had hemophilia.

I want to help others find resources to obtain the necessary information they need so they understand what hemophilia is if someone in their family has it. I want to share my story with them and tell them that they will still have a normal life and how to help them find what they need.

Being bilingual has helped me explain to my husband the information I have learned about hemophilia because he only speaks Spanish. I would love to continue helping all the spanish speaking families that need help as well as anyone else.

AWARDS

Lifetime Service Award Winner Shelley Jajeh

Written by Shelley Jajeh

I love Karate.

HFNC brings together a diverse range of people from all walks of life. I am honored to call all these people my "Hemophilia Family". It is through these connections that I was able to grow into the woman I am today. You see, prior to giving birth to my second son, Matthew, I was unaware of what hemophilia was or that I was a carrier of the hemophilia gene. This is where my story with hemophilia began....... I have been blessed with many things and the greatest of all these gifts are my sons. My eldest, Mark, does not have hemophilia; my youngest, Matthew, does. My second blessing was having Dr. Marion Koerper as Matthew's hematologist. I clearly remember the day she came to visit me in the hospital after I gave birth to Matthew. I was so distraught, scared, and uncertain of the life, if any, Matthew would have. Dr. Koerper gave me the tools I would need to raise Matthew to become a strong, healthy, man. For this I am truly grateful.

Dedicating my time as a volunteer to HFNC allows me to connect to the bleeding disorder community and contribute to a cause I care about. Volunteering is a two-way street: It benefits me and my family as much as HFNC. Volunteering continually encourages me to think of others and grows my compassion. I can use my skills in a productive way while helping others and making a difference. Volunteering increases my self-confidence, provides a sense of purpose, and makes me happy. The more I give, the happier I feel. When I do good for others and the community, I feel a natural sense of accomplishment. The better I feel about myself, the more I have a positive view on my life and my future goals (BLACK BELT by 60; currently 58 and testing for Brown Belt).

My husband Mark and me.

My sons Matthew and Mark.

My dogs

Congratulations to our 2020 Volunteer Award Winners!

Above and Beyond

Noriko Bouffard
Mosi Williams Kelly Yu
Tim Jeung Rob Toledo

Lifetime Service

Beth Connolly
Shelley Jajeh
Aban Patel

Special thank you to Mosi Williams for joining HFNC's Board of Directors in 2020!

NEWS

The Importance of Infusion

Written by Max Goldman

"You're going down!" My friends and I lined up on the blacktop and the ball was put into play. My face dripped with sweat as I ran and put my hands up. "I'm open!" Cole spirals the football right to me and it goes right into my grasp. Milliseconds later I crashed to the hard, hot pavement. My head made contact with the ground and I started to see stars. All of a sudden, people stopped playing and everyone gathered around me. One of my friends bolted to grab a staff member. Minutes later I was on a golf cart, ice pack in one hand and head in the other. My head was throbbing, at least the ice kept it cool.

Don't get me wrong, this experience would be hard for anyone to deal with, but as a teen with severe Hemophilia B, this injury was a lot more than a hospital visit and some ice. The biggest difference between Hemophiliacs and normal kids is that we have to infuse. Our bodies don't react to injuries like others' do, instead we must give ourselves those clotting factors. Long story short, for the next two weeks, I infused every other day until the swelling and pain subsided. This was the first thing that happened to me that made me realize the importance of infusion for a Hemophiliac.

When I was 8, I went to Camp Hemotion for the second time. I had a blast. The food was great, the activities were fun and the counselors and staff were more than welcoming. Before camp that summer I had tried to infuse alone probably three times without success, but this summer, I knew that I would succeed. Later that week when it was time for my infusion, I summoned all the courage I needed and did it. I was awarded the Big Stick award at the closing campfire for my accomplishment of infusing myself. When I walked on stage to claim my award, I knew that I was entering a new phase in my life as a Hemophiliac.

Before I learned how to infuse myself, I had a nurse come to my house every week at the same time to give me my prophy. Everytime he came, deep down I had a feeling that I was wasting his time with something that I could do myself. That's why it's so important to learn to infuse myself, because when I go to college, I won't have a home nurse to do my prophy for me every week.

Now, every Sunday, I get out my factor, set it up and infuse in a matter of minutes. I don't have to think about it or worry about it because I have made it a habit. For me, infusing every Sunday

Continued on Page 7

Camp then...

...Independence now.

is just like brushing my teeth every night. It would just feel unnatural not to infuse. To be honest, every now and then, there are times where I feel like infusing has no purpose. I experience so few bleeds that sometimes I don't feel the need to infuse at all. What is it doing to protect me? Does it really matter?

You have to understand the concept of breakthrough bleeds for it to really matter. If we were to stop infusing, our chances of random micro-bleeds would skyrocket. Infusing is important whether or not we see the effects of our efforts. Routine prophy protects us from the dangers of breakthrough bleeds as Hemophiliacs - whether mild, moderate or severe.

My family.

As a freshman in high school, I am only going to be living with my parents for the next four years. In college, they won't be there to protect me and to remind me to infuse. That's when building the habit of routine infusion comes into play. If I stop infusing because I disregard its importance, a whole new world of problems will emerge. Bleeds, hospital visits, injuries and pain. You get the picture. Whether we realize it or not, prophy plays a huge role in our lives as Hemophiliacs and not infusing is not an option because neglecting it has serious negative consequences.

So if you're ever tempted to skip an infusion, remember everything good it does to keep us going in our daily lives.


GO SEEK. GO EXPLORE.
GO AHEAD.
PEOPLE LIKE YOU. STORIES LIKE YOURS.
Explore more at HEMLIBRAjourney.com
Discover your sense of go. Discover HEMLIBRA.

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

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

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

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

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

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

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

What is HEMLIBRA?

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

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

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

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

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

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

How should I use HEMLIBRA?

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

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

What are the possible side effects of HEMLIBRA?

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

The most common side effects of HEMLIBRA include:

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

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

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

How should I store HEMLIBRA?

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

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

General information about the safe and effective use of HEMLIBRA.

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

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

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

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048
HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan

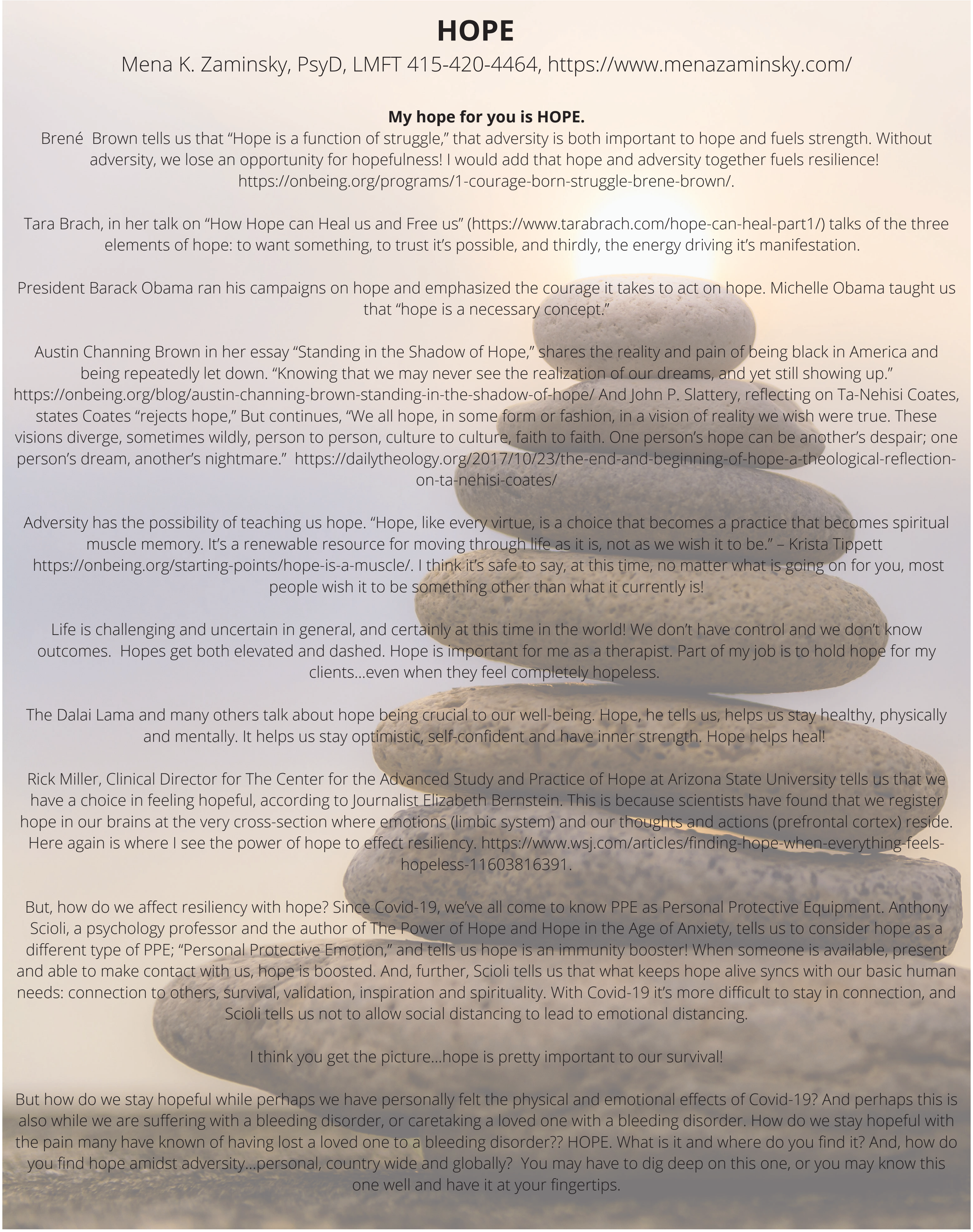
For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised: 10/2018

HEMLIBRA®
emicizumab-kxwh | 150 mg/mL
injection for subcutaneous use

Genentech
A Member of the Roche Group

HOPE

Mena K. Zaminsky, PsyD, LMFT 415-420-4464, https://www.menazaminsky.com/



My hope for you is HOPE.

Brené Brown tells us that “Hope is a function of struggle,” that adversity is both important to hope and fuels strength. Without adversity, we lose an opportunity for hopefulness! I would add that hope and adversity together fuels resilience! https://onbeing.org/programs/1-courage-born-struggle-brene-brown/.

Tara Brach, in her talk on “How Hope can Heal us and Free us” (https://www.tarabrach.com/hope-can-heal-part1/) talks of the three elements of hope: to want something, to trust it’s possible, and thirdly, the energy driving it’s manifestation.

President Barack Obama ran his campaigns on hope and emphasized the courage it takes to act on hope. Michelle Obama taught us that “hope is a necessary concept.”

Austin Channing Brown in her essay “Standing in the Shadow of Hope,” shares the reality and pain of being black in America and being repeatedly let down. “Knowing that we may never see the realization of our dreams, and yet still showing up.” https://onbeing.org/blog/austin-channing-brown-standing-in-the-shadow-of-hope/ And John P. Slattery, reflecting on Ta-Nehisi Coates, states Coates “rejects hope,” But continues, “We all hope, in some form or fashion, in a vision of reality we wish were true. These visions diverge, sometimes wildly, person to person, culture to culture, faith to faith. One person’s hope can be another’s despair; one person’s dream, another’s nightmare.” https://dailytheology.org/2017/10/23/the-end-and-beginning-of-hope-a-theological-reflection-on-ta-nehisi-coates/

Adversity has the possibility of teaching us hope. “Hope, like every virtue, is a choice that becomes a practice that becomes spiritual muscle memory. It’s a renewable resource for moving through life as it is, not as we wish it to be.” – Krista Tippett https://onbeing.org/starting-points/hope-is-a-muscle/. I think it’s safe to say, at this time, no matter what is going on for you, most people wish it to be something other than what it currently is!

Life is challenging and uncertain in general, and certainly at this time in the world! We don’t have control and we don’t know outcomes. Hopes get both elevated and dashed. Hope is important for me as a therapist. Part of my job is to hold hope for my clients…even when they feel completely hopeless.

The Dalai Lama and many others talk about hope being crucial to our well-being. Hope, he tells us, helps us stay healthy, physically and mentally. It helps us stay optimistic, self-confident and have inner strength. Hope helps heal!

Rick Miller, Clinical Director for The Center for the Advanced Study and Practice of Hope at Arizona State University tells us that we have a choice in feeling hopeful, according to Journalist Elizabeth Bernstein. This is because scientists have found that we register hope in our brains at the very cross-section where emotions (limbic system) and our thoughts and actions (prefrontal cortex) reside. Here again is where I see the power of hope to effect resiliency. https://www.wsj.com/articles/finding-hope-when-everything-feels-hopeless-11603816391.

But, how do we affect resiliency with hope? Since Covid-19, we’ve all come to know PPE as Personal Protective Equipment. Anthony Scioli, a psychology professor and the author of The Power of Hope and Hope in the Age of Anxiety, tells us to consider hope as a different type of PPE; “Personal Protective Emotion,” and tells us hope is an immunity booster! When someone is available, present and able to make contact with us, hope is boosted. And, further, Scioli tells us that what keeps hope alive syncs with our basic human needs: connection to others, survival, validation, inspiration and spirituality. With Covid-19 it’s more difficult to stay in connection, and Scioli tells us not to allow social distancing to lead to emotional distancing.

I think you get the picture…hope is pretty important to our survival!

But how do we stay hopeful while perhaps we have personally felt the physical and emotional effects of Covid-19? And perhaps this is also while we are suffering with a bleeding disorder, or caretaking a loved one with a bleeding disorder. How do we stay hopeful with the pain many have known of having lost a loved one to a bleeding disorder?? HOPE. What is it and where do you find it? And, how do you find hope amidst adversity…personal, country wide and globally? You may have to dig deep on this one, or you may know this one well and have it at your fingertips.

There is a commonality to us all, though our situations may be different. We look for ways to cope with our current lives, which are no longer “normal.” Life as we know it is very altered right now. We miss hugging, we miss our friends, socializing, families, communities, spiritual practices. We miss our in-person bleeding disorder fundraising walks; we miss our in- person bleeding disorder community retreats. We miss live music and performances and what seems at this moment in time, was a simpler life. And because of the current conditions, we may not have the support we had in the past.

Let’s look at what brings you hope? What makes you bounce back from despair? Perhaps it’s your meditation practice or your gratitude journal? Perhaps it’s your creative world...do you dance, sing, write poetry, paint, dig your hands in clay? Do you garden, cook, play with your pets? Do you spend time with your loved ones? Do you spend time in nature? What is it that makes your heart sing, gives you hope and creates resiliency in you? Sit quietly if you can and let yourself feel into a place of hopefulness.

There are so many signs of hope all around us! Sometimes in the simplest of places. For example, my sister gave me a Magnolia Magazine for my birthday. I was happily surprised at Joanne Gaines’ issue 16 “Rhythm.” She talks about anchoring to some ritual in your daily life and creating a sacred space for yourself. It could be as simple as taking 10 minutes for yourself every morning. Right now, I use my mornings to ride my bike and keep my gratitude journal. Both act as my sacred space and anchor, keeping me grounded, hopeful and resilient.

Let’s see if you can find an anchor or sacred space for yourself? Gaines has some recommendations that reflect my messages to my clients. Those include cooking, soaking in a bath, taking a 10-minute time out, lighting candles, meditating, singing, praying. What can you do in your day to help you stay the course of your life? What space can you give yourself to make it your sacred space...a space where you can enliven your sense of hopefulness!

I invite you to find yours by answering these hope inquiries:

1. Explore what is positive about your life
2. What are you grateful for?
3. Have you experienced anything that has helped you feel hopeful lately?
4. What is easeful in your life? Does that help you feel hopeful?
5. When do you feel most alive and open to possibilities?
6. What inspires you...helps you feel hopeful?
7. What provides you a sanctuary from the stresses and strains of daily life in an uncertain world that helps create resiliency in you?
8. What feeds and nourishes your soul and helps you feel hopeful?

My hope for you is to find what nourishes your soul in the most comforting of ways, and to incorporate more of it in your life to help you define your rhythm, encouraging your own touchstones/anchors and sacred spaces!

Below is one of my favorite poems about adversity and hope:

There is a brokenness out of which comes the unbroken,
A shatteredness out of which blooms the unshatterable
There is sorrow beyond all grief which leads to joy,
And a fragility out of whose depths emerges strength.
There is a hollow space too vast for words
Through which we pass with each loss.
Out of whose darkness we are sanctioned into being.
There is a cry deeper than all sound
Whose serrated edges cut the heart as we break open
To the place inside which is unbreakable and whole,
While learning to sing.
-Rashani

I invite you to change your relationship to sorrow while learning to sing!

We are in a moment in time we have never experienced in our lifetime. We must accept and understand we have no control over anything that’s happening. My hope for you is hope!Find your joy, meaning, sense of purpose. Pause, breathe and find the seeds of hope in your own life. They are there if you look!

NEWS

Camp Hemotion Brian Bircher Courage Award

We at HFNC are deeply honored that the family of Brian Bircher has chosen HFNC to create a new perpetual award in his memory. The Brian Bircher Courage Award will be given each year to the camper who demonstrates the most improvement or courage in the Camp Hemotion swimming program.

Written in loving memory by Cindy Bircher Rasmussen

I know that Brian will be smiling, I wish more people could have known Brian who passed away at the age of 41 six years ago. I'm sharing his story here as a way to do that and encourage all of our children with bleeding disorders to persevere and follow their dream.

During an interview in our home, a reporter from the local Southern California newspaper asked "If you could play any sport what would it be"? Without hesitation Brian answered "play baseball". But Brian, born with severe Hemophilia A, could not play his dream sport so at age 7, he began swimming instead.

Born in 1970, just after blood clotting factor was discovered, swimming was great for his joints and he quickly took to the sport. He joined the SoCal swim team in his hometown of Tustin California and began swimming competitively. He quickly excelled at the backstroke. By the age of 10 he qualified for the Junior Olympics, a prestigious competition in Los Angeles. He swam well in both the backstroke and IMhuge accomplishment for a youngster with severe hemophilia. His bleeds were not as frequent as many of the other boys and families we knew and we attributed that, in part, to his strong joints and the benefits of his swimming.

Brian attended Blood Brothers Hemophilia Summer Camp in Southern California for three years and he truly loved being there and having the freedom to just be with other kids like himself. By his teen years he learned to infuse himself, increasing his independence, resilience and self confidence.

In 1981 SoCal was invited to an international swim meet in Hong Kong and Brian was selected as one of the 15 team members to attend. Despite the ongoing concerns I had as his mother about traveling that far and the risks of managing a potential bleeding episode in another country, Brian was determined to go. I had previously learned to infuse Brian at home so we could treat him when needed. Brian competed in the first day of the

Continued on Page 14

Brian and I in 2010.

competition, but had a bleed that night and could not compete the second day. Nonetheless, it was a huge victory to see him swim well, be part of a great adventure, and manage his hemophilia successfully. The most amazing gift of the entire trip was, however, getting to meet Mother Teresa on the flight over, talking with her and getting her autograph.

In 1985 we were devastated to learn that Brian, and many thousands of other persons with hemophilia had acquired HIV through the needed but contaminated clotting factor. We, like so many families, learned to persevere. And Brian kept swimming.

Brian attended Servite High School in Anaheim California, joined the swim team, and

despite a grueling practice schedule, he enjoyed being part of a great team of young men. The summer before his senior year he approached us and said he wanted to play water polo, a rough sport akin to "football in the water'. Needless to say we were quite concerned about the dangers, but Brian persevered and we finally decided to let him have this opportunity despite our hesitations. He had a fantastic senior year and made incredible friends and cherished memories. He went on to play water polo for two years at Loyola Marymount University in Los Angeles; a miracle indeed for a young man with severe hemophilia!!

Brian was able to remain independent, employed and active until 2004 when his health

became too compromised for him to continue to work. He was a huge Phish fan, loved the 49ers, and lived for frequent visits to Hawaii to see his two precious young nephews Noa and Cody. Through everything, he never gave up and never lost his will to live. Brian passed away suddenly and unexpectedly April 19, 2014, just shy of his 44th birthday from complications of HIV and Hepatitis C. He left behind his father Ralph, two younger brothers Greg and Chad, and me.

Not a day passes that I don't think of him and his perseverance in the face of difficult odds. I am comforted to know that his story is being told and that his memory will live on through the Brian Bircher Courage Award. We give our heartfelt thanks to HFNC for making this possible.

2006 at his brother Chad's wedding - left to right - younger brother Greg, Chad and Brian.

STAFF SPOTLIGHT

Bryan Anderson, Associate Director HFNC

Written by Bryan Anderson

Anne, Mei Mei, and I at UC Berkeley in September

I came to HFNC back in 2015 on a four-month contract to organize the Hemophilia Walk (now called Unite for Bleeding Disorders). I was inspired by the people I met and the stories I heard, especially the ones about this cool sounding program called Camp Hemotion. I have now attended Camp Hemotion three times. I am always so impressed with the volunteers and HTC staff who pour their hearts into making that week so special for HFNC's youth.

Before joining HFNC, I directed afterschool programs and summer camps for eight and a half years in the Los Gatos-Saratoga Recreation Department. I developed my recreation programs around the core belief that everyone has within them an infinite potential and it is our responsibility to create an environment where that potential can take shape. I hope to bring that same spirit to the programs, services, and community at HFNC.

Quarantine life has been interesting to say the least. Working from home with my wife, Anne, my brother-in-law, Michael, who is on the autism spectrum, and my dog, Mei Mei. Our 1 bedroom apartment in Oakland has never felt so small. We often head over to UC Berkeley to enjoy sitting on the lawn and just getting outside for break every once in a while. Hopefully we can find safe spaces for the winter time, too.

Hang in there everyone! I can't wait to get back to hugs and in person gatherings as soon as it is safe to do so.

2021 TFF Retreat 4/23-4/25

Register @ hemofoundation.org/events

The Hemophilia Foundation of Northern California

FOR ALL BLEEDING DISORDERS

"I felt confident and strong going into my surgery two days after that retreat"

"I took the new bag to the hospital with me, proud to sport my new swag! ;)"

"Thank you for creating a meaningful gathering for us all"

THE FEMALE FACTOR
Affected and Connected

Takeda

BAYER

CSL Behring
Biotherapies for Life™

Pfizer

HFA
Hemophilia Federation of America

SANOFI GENZYME

octapharma

Genentech
A Member of the Roche Group

Brothers

UCDAVIS HEALTH

UCSF Benioff Children's Hospitals
Oakland | San Francisco

novo nordisk®

CSL Behring
Biotherapies for Life™

The Female Factor presents
a webinar
Join the Community Lounge
4:30-5pm PST & 6-6:30pm PST
Come say hi and catch up

Common Factor Program

Milybet Montijo-Cepeda is a special needs teacher, a wife, and a mother of a young son, Omar. Omar has severe hemophilia A – and Milybet has mild hemophilia A. Omar's diagnosis was confirmed at birth, Milybet was not so lucky – she was 39 years old before receiving her diagnosis. "There are approximately 18,000 boys diagnosed with hemophilia in the U.S. today, "says Jerry Powell, Medical Director of Coagulation, U.S. Commercial Operations at CSL Behring, a global biotherapeutics company driven by its promise to help people with serious medical conditions lead full lives. "For every boy living with hemophilia, there is a Mom, sister or aunt who is potentially at risk for the disease. It's critical that we help raise awareness and educate these families on the importance of receiving an accurate diagnosis."

January 13, 2021 @ 5pm

www.hemofoundation.org/events

NEWS

Familia de Sangre 2020: Septiembre 18-19, 2020

FAMILIA DE SANGRE
CALIFORNIA 2020

Del 18 al 19 de septiembre de 2020, la Fundación de Hemofilia del Sur de California, la Fundación de Hemofilia del Norte de California, la Fundación de Hemofilia de California Central y la Asociación de Hemofilia del Condado de San Diego con nuestros invitados de la Asociación Puertorriqueña de Hemofilia y Condiciones de Sangrado acogió la 4ª Conferencia Anual Familia de Sangre. Aunque se llevó a cabo virtualmente, ¡más de 350 familias se unieron a nosotros para un fin de semana de educación, empoderamiento y apoyo!

La conferencia comenzó el viernes por la noche con una sesión de apertura moderada por el ex miembro de la mesa directiva de NHF, Jorge de la Riva, y el congresista Lou Correa, representante de los Estados Unidos del distrito # 46 del Congreso. Luego, los asistentes visitaron una emocionante sala de exhibición virtual seguida de una actuación del Mariachi Silvestre y una noche de juegos familiares con DJ Rick Maza, donde las familias escucharon algunas de sus canciones favoritas o ¡bailaron toda la noche!

El sábado comenzó con sesiones muy informativas y muy concurridas que incluyeron inmigración, terapias emergentes, planificación patrimonial y fiduciaria para personas con condiciones crónicas, VWD y manejo del dolor, entre muchos otros. Se compartieron historias personales y se derramaron lágrimas durante el panel Culpa Intachable para madres que se conectaron con otras mujeres de la comunidad moderada por Erika Bocanegra. Después de la conferencia, los asistentes pudieron continuar conectándose y elegir uno de los seis interesantes seminarios web comunitarios que se llevaron a cabo los miércoles por la noche y que fueron patrocinados por Takeda, Biomarin, Genentech, Sanofi Genzyme y Novo Nordisk.

Este año, FDS se complacio en darle la bienvenida a miembros de la comunidad de habla hispana de más de 10 estados y Puerto Rico. Estamos muy agradecidos con todos los que asistieron e hicieron de la conferencia virtual de este año un gran éxito y esperamos conectarnos con ustedes en persona o virtualmente para Familia de Sangre 2021 del próximo año. Gracias a la Federación de Hemofilia de América por su asociación.

También estamos agradecidos con el patrocinador de Titanium Takeda y sus presentadores del equipo educativo de habla hispana: Annabelle García, Susana Escojido, RN, Maria Raquel Tovar y Patricia Espinoza-Thompson.

Patrocinadores Platino: Novo Nordisk, Sanofi Genzyme, BioMarin y Genentech; Patrocinador Oro: CSL Behring; Patrocinador Plata: Bayer; Patrocinadores Bronce: Octapharma, CVS Specialty, Pfizer y UniQure. ¡Gracias a todos nuestros increíbles Voluntarios!

TITANIO

Takeda

PLATINO

BIOMARIN Genentech A Member of the Roche Group novo nordisk SANOFI GENZYME

ORO

CSL Behring Biotherapies for Life

PLATA

BAYER

BRONCE

CVS specialty octapharma Pfizer uniQure

PUESTO

accredo Brothers Healthcare MEDEXUS PHARMA OPTUM

PROFUSION SOLEO HEALTH Spark

EN ASOCIACION CON

Sangamo HFA

CALENDAR

JAN

1/1/21	New Years Day	
1/11/21-1/13/21	Unite Rally	Virtual
1/12/21	Board Meeting	Virtual
TBD	NACCHO	Phoenix, AZ
TBD	Board Retreat	Virtual / TBD

FEB

TBD	NHF Chapter Leadership	TBD
2/9/21	Board Meeting	Virtual
2/27/21	Rare Disease Day	TBD

MAR

TBD	HCC Health Summit	TBD
3/1/21-3/31/21	Bleeding Disorders Awareness Month	
3/3/21-3/5/21	NHF Washington Days	
3/9/21	Board Meeting	Virtual
3/14/21	Walk Launch	TBD
TBD	Emerging Therapies	

APRIL

4/4/21	Easter	
TBD	Region IX	TBD
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
5/14/21-5/16/21	Family Ed Weekend	Virtual

JUN

6/13/21-6/19/21	Camp Hemotion	Virtual/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/

HEMOPHILIA FOUNDATION
OF NORTHERN CALIFORNIA
6400 Hollis St · Suite 6
Emeryville, CA 94608

PRSRT STD
U.S. POSTAGE
PAID
PERMIT NO. 316
SACRAMENTO, CA

The Hemophilia Foundation of Northern California
FOR ALL BLEEDING DISORDERS

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

PLEASE NOTE: The companies whose advertisements are listed herein have purchased this space, and are NEVER provided with members' names, addresses or any other personal details. Paid advertisements and paid inserts should not be interpreted as a recommendation from HFNC, nor do we accept responsibility for the accuracy of any claims made by paid advertisements or paid inserts.

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 Foundation of Northern California, or those of the editorial staff.

MATERIAL PRINTED IN THIS PUBLICATION MAY BE REPRINTED WITH THE EXPRESS PRIOR WRITTEN PERMISSION FROM THE EXECUTIVE DIRECTOR. SPRING, SUMMER, FALL OR WINTER WITH YEAR MUST BE INCLUDED.

Hemophilia Foundation of Northern California is a 501(c)(3) non-profit. Donations are tax-deductible, much needed and appreciated.

BOARD OF DIRECTORS

Dawn Pollard
BOARD PRESIDENT

Peter Barbounis
VICE PRESIDENT

Patty Jewett
SECRETARY

Kris Contratto
TREASURER

Marion Koerper MD
Susan Kuhn
Tony Materna
Robert Seaton
Nancy Hill
Mosi Williams
BOARD MEMBERS

STAFF

Andrea Orozco
EXECUTIVE DIRECTOR

Bryan Anderson
ASSOCIATE DIRECTOR

Ashley Gregory
EDUCATION AND ADVOCACY DIRECTOR

CONTACT INFORMATION

6400 Hollis Street, Suite 6
Emeryville, CA 94608

Office hours: Mon-Fri,
9:30 a.m. to 4:30 p.m.

www.hemofoundation.org
infohfnc@hemofoundation.org

(510) 658-3324 phone
(510) 658-3384 fax

Visit our website at www.hemofoundation.org for important information.
If you would like to advertise in the next issue, please contact the foundation.