

Infusions

WINTER EDITION

HFNC Family Camp 2020

By Janice Cole



NEWS

I served as a volunteer at Family Camp this year, along with my son, Owen. I have two boys, now both young men, with Severe Hemophilia A. My family has been involved in the bleeding disorders community in various capacities over the years, both at the national level and the local level. I still vividly remember my first event over twenty years ago. I was the scared parent of a beautiful little boy, Ian, newly diagnosed with Hemophilia. I attended, along with my husband, the national NHF conference held in New Orleans. It's hard to express what I gained from my first encounter with the people within the bleeding disorders community, but I left that event with a sense of hope. I felt an instant connection with those I met. I also felt understood, accepted, and empowered. I came to realize that although Hemophilia would always be a part of our lives, it did not have to consume

our lives. For the first time since being diagnosed, I believed our son could still have a rich, full life despite his condition.

Family camp was held at Camp Arroyo, nestled in the foothills of Livermore, and made possible not only by HFNC but the generosity of The Taylor Family Foundation. I was grateful for the experience of volunteering for the second time with this wonderful group of staff, fellow volunteers, and families. It was wonderful to witness the return of so many families and to meet so many newcomers. This year the theme of camp was The Lion King. Families engaged in a range of activities including music therapy, rock climbing/ropes course, equine therapy, a drumming circle, campfire activities, and parent support/ educational sessions.

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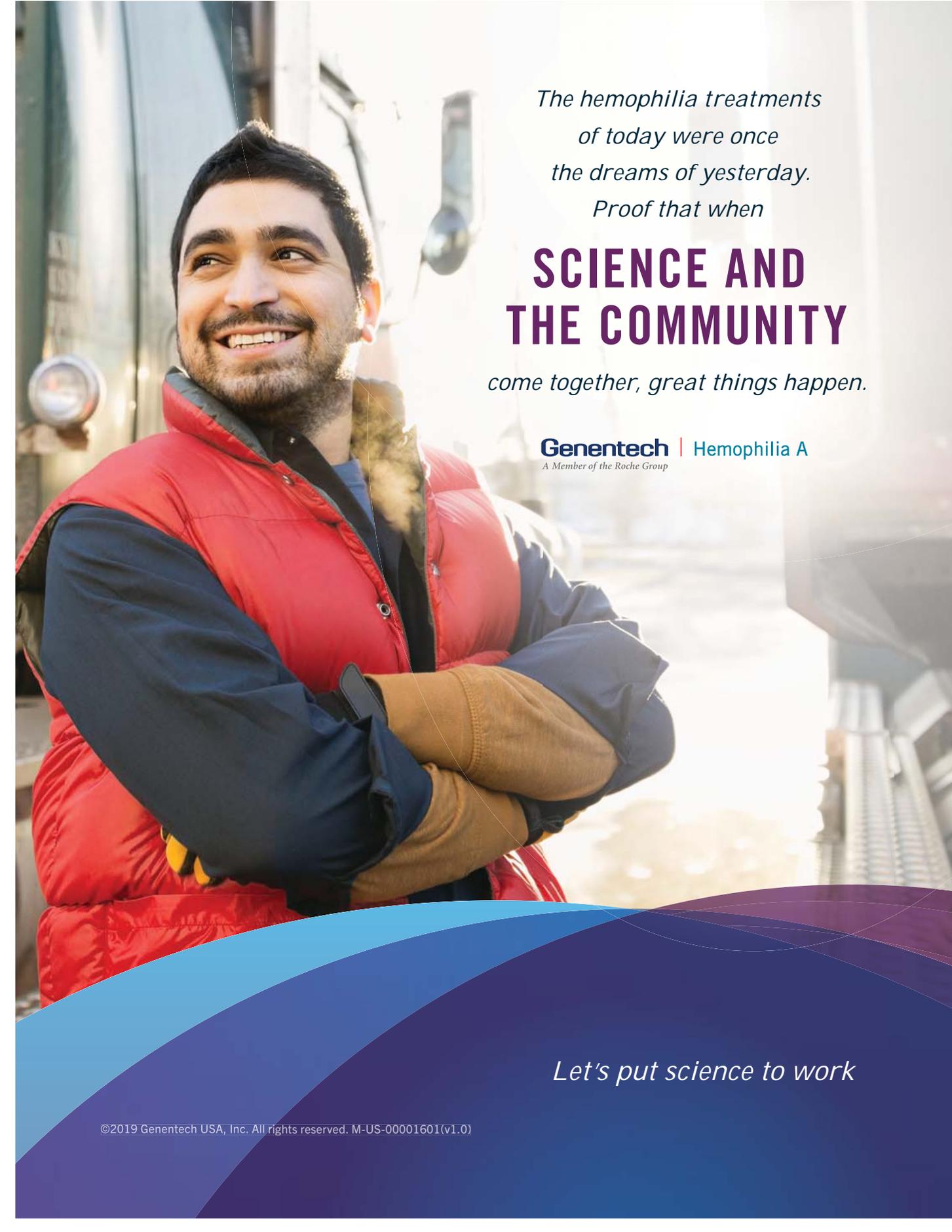
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*The hemophilia treatments
of today were once
the dreams of yesterday.
Proof that when*

SCIENCE AND THE COMMUNITY

come together, great things happen.

Genentech | Hemophilia A
A Member of the Roche Group

Let's put science to work

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Why I Walk

Join our Unite for Bleeding Disorders Walk on May 17, 2020
Lake Merritt Pergola, 9am-12pm (8am registration)

Hi, my name is Noriko and I'm participating in the **Unite for Bleeding Disorders** this spring (May 17th) I walk for the Unite for Bleeding Disorders for many reasons:

To raise funds for the Hemophilia Foundation of Northern California - because I want to ensure they can continue to provide the services and access to care for other families with bleeding disorders

To raise awareness for bleeding disorders in my own community and for those who see us at the walk

Because **the walk is a fun family event** and has become a family tradition since 2013

My son Keiji, who is a mild type A hemophiliac, to show him that there are others like him and that he can do something to give back to others with bleeding disorders in need

Because **it's our way to give back and pay it forward**. It's good to volunteer and give back to a great cause, one that is so deeply personal to our family.

Hoping that some of the reasons that I gave resonate with you and inspire you to consider coming out to walk with us! Please consider signing up at <https://www.uniteforbleedingdisorders.org/event/NorCal> to give back and make a difference for a great cause!

Noriko Bouffard Team Captain of Keiji's All Star's 
 (Co-Chair of the Unite Walk)

Create your own elevator pitch and register your team at

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

Elevator pitch pointers:

- Keep it crisp – 30sec max
- Make it personal – to make it memorable
- Have an "ask" – open or closed (what is your goal? To raise funds and get folks interested in walking with you)
- **Structure:**
 - Who – Quick Intro to you
 - What – What do you want to tell them (i.e. the Walk, HFNC, where the funds go)
- Why – Why are you doing this? (personalize it)
- Close – Have the ask – (what is your goal? I.e. ask for donation or ask for people to participate)



Dear Community Advocates,

We are excited to share our advocacy efforts to declare March, 2020 as Bleeding Disorders Awareness Month across Northern California! March is just around the corner, and with your help, we hope to raise awareness and money for bleeding disorders within YOUR communities.

Nationwide, the goal of declaring March as Bleeding Disorders Awareness Month is to spread awareness of bleeding disorders to the general public and raise money for further research. As a community advocate, we are asking for your help. To do this, we've come up with various events and materials for you to share with your community. It's up to YOU to choose how you're going to spread the word in your neighborhood. Please see below for more details regarding the resources and ideas we would like to share to make March a success.

 **Red Ties or Aprons:** The goal is to spark conversation and spread the word about Bleeding Disorders by asking local retailers and restaurants to wear red ties or aprons in March.

- Hemophilia Foundation of Northern California (HFNC) can provide: red ties, aprons, and educational materials paid for and shipped to you
- Your responsibility: Distribute red ties or aprons and educational brochures in late February or early March.

 **Local Restaurant Fundraisers** - Dine and Dime throughout the month of March.

- HFNC can provide: templates for contacting restaurants
- Your responsibility: contact restaurants and coordinate fundraisers

 **Declaration of March as Bleeding Disorders Awareness Month and light up town hall red:**

Local governments can declare March "Bleeding Disorders Awareness Month"

- HFNC can provide: proclamation template
- Your responsibility: conduct research and coordinate with local government officials

 **School "Wear Red" days**

- Your responsibility: provide educational materials to schools and work with school administration

We are also excited to share facts, figures, and resources on the Hemophilia Foundation of Northern California's social media throughout the month of March. However, the success of our first-ever advocacy effort of this type is largely dependent on you as the community advocates. Here's what we are asking:

Please let us know which of the previously listed ideas sound most exciting and feasible for you to implement in your community. Once we've received your responses, we can get to work on ordering supplies, such as aprons or ties, and will be able to follow up with additional resources.

Once again, we are thrilled to continue our efforts to spread awareness of bleeding disorders and can't wait to see what a success March, 2020 will be! 

Did you know?

Did you know the Hemophilia Federation of America is accepting artifacts that may be accepted into **The SMITHSONIAN?**

Hemophilia Federation of America has already collected (and donated) a number of artifacts and documents from our community's history, but we still need your help!

Do you have old family photos depicting the reality of life with a bleeding disorder? Did someone keep diaries or journals that reflect a personal journey? Are there old braces and bottles of factor stashed away in the attic? Even a stained handkerchief? We're looking for personal items as well as newspaper articles, newsletters, posters, and other artifacts that tell our story of endurance and resilience.

You can submit a photo of something you have that may be added to our collection through the HFA website. A committee will review the submissions and work with you to collect and

return items. Alternately, you may make the donation to Hemophilia Foundation of Northern California who may pass it along to HFA.

Not all items that we receive are accepted by the Smithsonian. The Smithsonian are really interested in physical items, like old bottles of medicine, medical devices, clothing, and handwritten journals. These items have the highest likelihood of making it into the final collection.

Because of the legalities of ownership in donating to a museum, we ask that donors complete the deed of gift form to transfer ownership to HFA. We will then transfer ownership of donated items to the Smithsonian. 

Please contact HFNC for a deed of gift form or to learn more, visit www.hemophiliated.org and <https://www.hemophiliated.org/understanding-bleeding-disorders/history-and-future/2019-history-exhibit/>

Family camp marks my first involvement in the bleeding disorders community after taking a several year hiatus. The truth is I took a step back because I was striving to keep up with the demands of a rigorous graduate program while also trying to cope with a worsening chronic health condition. The demands proved to be too much, along with my inability to accept the toll it was taking on my health. The result was I nearly lost my life two years ago—I ended up in the hospital and spent several weeks trying to recover—physically and emotionally. I dropped out of graduate school and lost several relationships. I was left with a sense of shame, despair, hopelessness, and failure. It has been a long road to recovery, and a truly humbling experience. Thanks to the support of a wonderful husband, my children, and others, I am entering life again—but in a different capacity.

There are many challenges of living with a chronic health condition. Dealing with my children's bleeding disorder and my own compromised health has brought me to my knees—over and over again. And I know I am not alone in that experience. Every person within this community knows what I speak of. And it is in large part through the support of this wonderful community that I have the courage to keep standing up. It is an empowering and healing experience to come together to give and receive support, share in our pain, and learn to find joy.

As we gathered by the campfire for the talent show and to make s'mores, we listened to the Song "The Rainbow Connection," a classic song with a timeless message. It's about keeping our curiosity, hopes and dreams alive. Also, it seems to say that by searching for something bigger than ourselves, we find ourselves. It reminded me that by letting go of the way we think life should be, we can open ourselves to discover new paths and dreams—and have the courage to go into the unknown. Paradoxically, through coming together and feeling a sense of belonging we find that our health challenges do not need to define us. We are each unique, precious individuals with hopes, dreams, and aspirations. Living with a chronic health condition brings us inevitably closer to loss and a sense of mortality; paradoxically it also invites us to live more fully in the moment and embrace the life we are given.

One of the most memorable activities of camp was the drum circle. The facilitator exclaimed, "If you have a heartbeat, you can drum!" I loved his encouraging, inclusive message!! Thus, attendees gathered and played their instruments with abandon—full of self-expression. The group was skillfully led thru a series of

rhythm explorations and songs. The energy and joy in the room was palpable. The moment that stood out the most was when children were invited to take turns leading the drum circle—controlling the group by raising and lowering their hands taking command of a series of group crescendos and decrescendos. I was particularly moved when a little boy, who shared the name of my own son, Owen, led the group. As "little Owen" happily took charge, he confidently grinned—almost bursting with a sense of power. Chronic health conditions can sometimes leave one feeling weak and powerless. It was beautiful to see a moment where strength and power were taken back—with the help of community. Despite a room full of mostly inexperienced musicians—there was a sense of synchronicity, connectedness, and creativity. The result was a deeply therapeutic effect—and living in the joy of the moment with one another.

Admittedly, I used the excuse of wanting to get my son involved in the bleeding disorders community to justify my own recent involvement. "It would be good for him," I thought. I didn't think I had much to offer—and I was forced to confront feelings of self-doubt and low self-worth as a result of some difficult life experiences. I finally decided to let go of any preconceived notions of how to be a "good" volunteer and decided to just roll with it, so to speak. In a moment of letting go, I decided the best thing I could offer was presence and a willingness to connect with others. In the process of opening to the experience, I was reminded of why I love this community so much—because of all the support, acceptance, and compassion it has to offer. I owe a lot of my growth as a parent and as an individual to this community—and I needed to be reminded of that. I notice the best in people when I participate at these events—and I believe my own participation helps me to be a better person and to find a sense of purpose. It helped me to trust that I, along with other attendees, would get what we needed from the experience. I learned that sometimes we must step out of our comfort zone and be willing to show our vulnerability in order to heal and grow.

I am so grateful I had the opportunity to take part in the HFNC family camp again this year. I enjoyed spending the weekend in a beautiful setting with so many wonderful individuals and families. These experiences with the Hemophilia Foundation have a way of making even the unbearable bearable. Together we can lift each up and believe that despite the struggle, life can be good. 

CALENDAR

Jan 1, 2020	New Years Day	
Jan 14, 2020	Board Meeting In Person, HFNC Office/call in 510-972-9851	HFNC
Jan 15, 2020-Jan 17, 2020	Teen Winter Summit, TBD	
Jan 16, 2020-Jan 19, 2020	NACCHO, Phoenix, AZ	NHF
Jan 17, 2020-Jan 19, 2020	Family Camp, Camp Arroyo, Livermore, CA	HFNC
Jan 25, 2020	Board Retreat, TBD	HFNC
Feb 11, 2020	Board Meeting Call In 510-972-9851	HFNC
Feb 17, 2020	President's Day	
Feb 23, 2020	Asian Infusion, TBD	HFNC
Feb 26, 2020-Feb 28, 2020	NHF's Washington Days, Washington DC	NHF
Feb 28, 2020	Rare Disease Day	
Mar 1, 2020-Mar 31, 2020	Bleeding Disorder Awareness Month, Local cities in California	HFNC
Mar 1, 2020-Mar 31, 2020	Bleeding Disorder Awareness Month, Statewide California	HCC
Mar 7, 2020	Emerging Therapies Forum, Stanford University	HFNC
Mar 9, 2020-Mar 12, 2020	Chapter Leadership, Dallas, TX	NHF
Mar 10, 2020	Board Meeting In Person, HFNC Office/Call In 510-972-9851	HFNC
Mar 29, 2020	Annual Meeting and Community Crab Feed, Columbo Club	HFNC
April 2, 2020-April 5, 2020	YETI Conference	
April 4, 2020-April 6, 2020	Region IX, Torrance, CA	
April 12, 2020	Easter	
April 14, 2020	Board Meeting Call In, 510-972-9851	HFNC
April 17, 2020	World Hemophilia Day	
April 19, 2020	Family Education Day/WHF Celebration, Madera	HFNC
April 23, 2020-April 26, 2020	HFA Symposium, Baltimore, MD	HFA
TBD	Future Leaders/LEG Day, Sacramento, CA	HCC
May 1-May 3, 2020	Bleeders TBD	HFNC
May 5, 2020	Cinco De Mayo	
May 17, 2020	Unite for Bleeding Disorders Walk, Lake Merritt Pergola, Oakland, CA	HFNC/Unite for BD
May 25, 2020	Memorial Day	
June 13, 2020-June 14, 2020	Camp Hemotion Staff and Counselor Training, Camp Oakhurst, Coarsegold, CA	HFNC
June 14, 2020- June 20, 2020	Camp Hemotion, Camp Oakhurst, Coarsegold, CA	HFNC
June 14, 2020 -June 17, 2020	World Hemophilia Congress, Kuala Lumpur	WFH
June 27, 2020	Vines & Hops Silent Auction, Wine & Beer Tasting, TBD	HFNC
July 4, 2020	Independence Day	
July 17, 2020	July 19, 2020 BLeaders, TBD	HFNC
July 17, 2020	Amazon Prime Day	
July 20, 2020	July 31, 2020 HFNC Staff Strategic Planning, HFNC Office	HFNC
Aug 5, 2020-Aug 8, 2020	NHF Bleeding Disorders Conference, Atlanta, GA	NHF
Aug 31, 2020	Golf Tournament, Ruby Hill Golf Club	HFNC
TBD	HCC Health Summit, Sacramento	
Sept 7, 2020	Labor Day	
Sept 17, 2020-Sept 19, 2020	Familia de Sangre, TBD/Los Angeles	HFNC/CCHF/HFNC/HASDC
Oct 4, 2020	San Jose Color Relays, San Jose, CA	HFNC/Unite for BD
Oct 12, 2020	Columbus Day	
Oct 16, 2020	Oct 18, 2020, The Female Factor 6th Annual Retreat, TBD	HFNC/HASDC/HFNV
Nov 11, 2020	Veteran's Day	
TBD	Men's Retreat	HFNC/CCHF
TBD	NHF Insurance Reimbursement Summit, Baltimore, MD	NHF
Nov 26, 2020- Nov 27, 2020	Thanksgiving Holiday	
December 1, 2020	World AIDS Day	
December 1, 2020	Giving Tuesday	
December 5, 2020	Oakland Winter Community Gathering, TBD	HFNC
December 6, 2020	Posada Navidena, South Bay TBD	HFNC
TBD	Fresno Winter Community Gathering, Valley Children's Hospital, Madera, CA	HFNC
December 25, 2020	Christmas Day	

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):

HFSA 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.hemophiliated.org/>

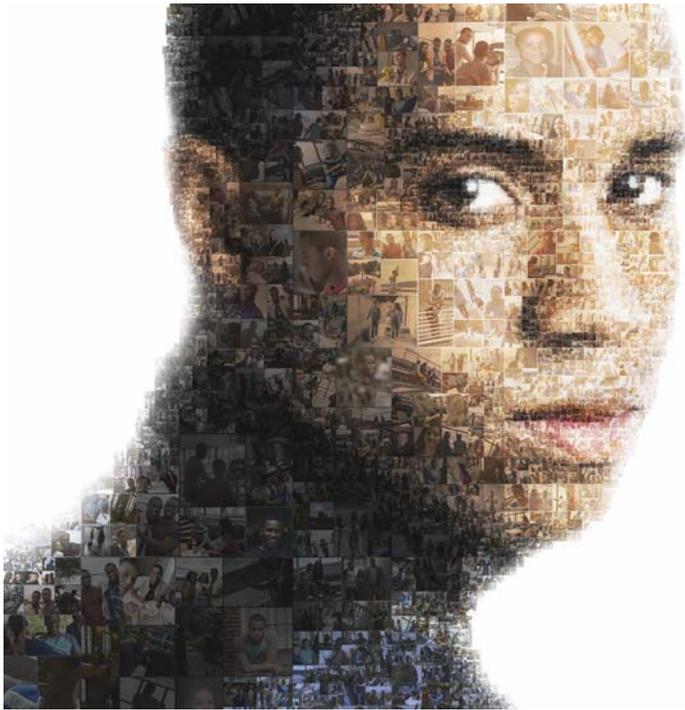
HCC Hemophilia Council of California
<https://www.hemophiliaca.org/>

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/>



ADYNOVATE
[Antihemophilic Factor
(Recombinant), PEGylated]

REAL LIFE. REAL BLEED PROTECTION.*
AdynovateRealLife.com

HEMOPHILIA A IS A PIECE OF YOU. NOT ALL OF YOU.

ADYNOVATE® is a treatment that can be personalized to fit your lifestyle so you have more time to spend doing the other things that also make you, you. It has a simple, twice-weekly dosing schedule on the same 2 days every week.^{1,2}

*In clinical trials, ADYNOVATE demonstrated the ability to help prevent bleeding episodes using a prophylaxis regimen.

No actual patients depicted.

ADYNOVATE twice-weekly prophylaxis prevented or reduced the number of bleeds²

ADYNOVATE was proven in 2 pivotal clinical trials to prevent or reduce the number of bleeding episodes in children and adults when used regularly (prophylaxis)²

- **Children Under 12 Years:** This study evaluated the efficacy of ADYNOVATE twice-weekly prophylaxis and determined the ability to treat bleeding episodes for 6 months in 66 children under 12 years old who received 40–60 IU/kg of ADYNOVATE prophylaxis treatment²
 - During the 6-month study in children under 12, those receiving twice-weekly prophylaxis treatment experienced a median¹ overall ABR³ of 2.0
 - 0 bleeds in 38% (25 out of 66 patients) during 6 months on twice-weekly prophylaxis

¹Median is defined as the middle number in a list of numbers arranged in numerical order.

²ABR=annualized bleed rate, the number of bleeds that occur over a year.

³Per-protocol patients were assigned to the prophylactic group and treated with their originally assigned dose for the entire duration of the study.

ADYNOVATE Important Information

What is ADYNOVATE?

- ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital factor VIII deficiency).
- Your healthcare provider (HCP) may give you ADYNOVATE when you have surgery.
- ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADYNOVATE?

Do not use ADYNOVATE if you:

- Are allergic to mouse or hamster protein.
- Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)].

Tell your HCP if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

What should I tell my HCP before using ADYNOVATE?

Tell your HCP if you:

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

- **Adolescents and Adults 12 Years and Older:** This study evaluated the efficacy of ADYNOVATE in a 6-month study that compared the efficacy of a twice-weekly prophylactic regimen with on-demand treatment and determined hemostatic efficacy in the treatment of bleeding episodes in 137 patients. These adolescents and adults were given either ADYNOVATE prophylaxis twice-weekly at a dose of 40–50 IU/kg (120 patients) or on-demand treatment with ADYNOVATE at a dose of 10–60 IU/kg (17 patients). The primary study goal was to compare ABR between the prophylaxis and on-demand treatment groups²
 - 95% reduction in median overall ABR (41.5 median ABR with on-demand [17 patients] vs 1.9 median ABR with prophylaxis [120 patients])
 - 0 bleeds in 40% (40 out of 101 per-protocol⁵ patients) during 6 months on twice-weekly prophylaxis

What important information do I need to know about ADYNOVATE?

- You can have an allergic reaction to ADYNOVATE. Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.
- Do not attempt to infuse yourself with ADYNOVATE unless you have been taught by your HCP or hemophilia center.

What else should I know about ADYNOVATE and Hemophilia A?

- Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

What are possible side effects of ADYNOVATE?

- The common side effects of ADYNOVATE are headache and nausea. These are not all the possible side effects with ADYNOVATE. Tell your HCP about any side effects that bother you or do not go away.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see Important Facts about ADYNOVATE on the following page and discuss with your HCP.

For Full Prescribing Information, visit www.adynovate.com.

References: 1. Valentino LA. Considerations in individualizing prophylaxis in patients with haemophilia A. *Haemophilia*. 2014;20(5):607-615. 2. ADYNOVATE Prescribing Information.

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ADYNOVATE
[Antihemophilic Factor
(Recombinant), PEGylated]

Patient Important facts about

ADYNOVATE® [Antihemophilic Factor (Recombinant), PEGylated]

This leaflet summarizes important information about ADYNOVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADYNOVATE. If you have any questions after reading this, ask your healthcare provider.

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

Do not attempt to do an infusion to yourself unless you have been taught how by your healthcare provider or hemophilia center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing ADYNOVATE so that your treatment will work best for you.

What is ADYNOVATE?

ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

Who should not use ADYNOVATE?

You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)]

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

How should I use ADYNOVATE?

ADYNOVATE is given directly into the bloodstream.

You may infuse ADYNOVATE at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADYNOVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADYNOVATE to use based on your individual weight, level of physical activity, the severity of your hemophilia A, and where you are bleeding.

Reconstituted product (after mixing dry product with wet diluent) must be used within 3 hours and cannot be stored or refrigerated. Discard any ADYNOVATE left in the vial at the end of your infusion as directed by your healthcare professional.

You may have to have blood tests done after getting ADYNOVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

How should I use ADYNOVATE? (cont'd)

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

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

You should tell your healthcare provider if you:

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

What are the possible side effects of ADYNOVATE?

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The common side effects of ADYNOVATE are headache and nausea. Tell your healthcare provider about any side effects that bother you or do not go away.

These are not all the possible side effects with ADYNOVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADYNOVATE and Hemophilia A?

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

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

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADYNOVATE. The FDA-approved product labeling can be found at www.ADYNOVATE.com or 1-877-825-3327.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

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S47033

Danny's Dose Changing Rules & Saving Lives

There are many things we count on without thinking about it; when we stop at a red light, we expect it to turn green, when we open the window, we expect to feel air and when we call 911 in an emergency, we expect to receive appropriate care. When a California parent's son fell from a two story window, she rushed to administer his clotting factor for his severe factor VIII deficiency, or Hemophilia, and she was admonished by paramedics despite showing his medic-alert bracelet and medication with prescription. She was threatened with arrest. Unfortunately, in California, many rare patients with life saving medications and emergency protocols cannot expect to receive the care they need from paramedics and emergency room staff due to a discrepancy in California's Emergency Medical Services. This gap in care can lead to waiting for emergency doses of bleeding disorders medication in the field by paramedics and/or in the emergency room by medical personnel.

Waiting to receive emergency bleeding disorders medication can lead to unwanted consequences, including nerve damage and anemia from prolonged bleeding, loss of limb, organ, and in some cases, life. When emergency treatment is needed for our rare conditions, we may receive the very opposite of what we expect, which could be a delay in care due to medical personnel informing us they cannot follow our specialists treatment plan for our rare condition.

Emergency medical personnel and treatment room staff can generally be counted on to provide standard of care for conditions known and routine and they want to help, that is why they got into the profession in the first place. However, patients with rare conditions and their families are finding that access to the emergency treatment plan ordered by their specialists is, at times, not followed. This can result either from emergency vehicles not stocking rare, life saving medications or paramedics and emergency facilities not being familiar with rare, life saving, self-carried medications or specialized protocols and are unable to administer either due to liability or lack of familiarity with a medication, condition or both. Paramedics and emergency facility personnel want to follow specialists orders and protocols, but may require additional knowledge and training to ensure patients specialists standards of care are followed in an emergency.

Paramedics and National Emergency Medical Services leaders are partnering with Danny's Dose Alliance, (Dannysdose.com)

whose mission is to raise awareness of the current gap in Emergency Treatment for all with special medical needs, to change the current protocols, help educate emergency service personnel and educate affected families in proper emergency planning and protection. To address this concern, they are making headway across the nation to provide education, training and implementation to ensure rare patients have access to their life saving medications and protocols. In Missouri, 2014, Darlene Shelton naturally assumed that when her grandson was diagnosed with hemophilia B, in the event of an emergency he would have his clotting factor administered according to his specialists orders. She was shocked to learn that not only were paramedics not allowed to administer her grandsons life saving medication, but the nearest emergency room qualified to treat him was two and a half hours away by helicopter. Her family decided they could address this concern by



contacting local legislators and alerting them of the situation. In 2018, Missouri became the first state in the nation to allow the administration of specialists protocols and self-carried, life saving medications in an emergency by paramedics and emergency facility treaters. Subsequently, in 2019, Minnesota became the second state in the nation to pass the same legislation. This has sparked a conversation for Danny's Dose to begin partnering with National paramedic and emergency treaters across the nation to provide education, training and implementation of protocols to emergency treaters and standards of care for patients with rare conditions.

What You Can Do To Help Yourself/Your loved One/Person(s) You Care For

Patients and organizations such as EveryLife Foundation, Rare Disease Legislative Advocates, Global Genes, and NORD (National Organization of Rare Diseases) have been working with Danny's Dose with the goal of passing similar legislation which would enable patients with rare conditions to have their specialists orders followed in an emergency by paramedics and emergency room providers. Until this lack of care is corrected, and beyond, you can help you or your loved one with a rare condition with

Continued on Page 8

Unite

for Bleeding Disorders

Lake Merritt Pergola | Oakland, CA

JOIN US | MAY 17, 2020

9AM - 12PM

Register at

www.uniteforbleedingdisorders.org



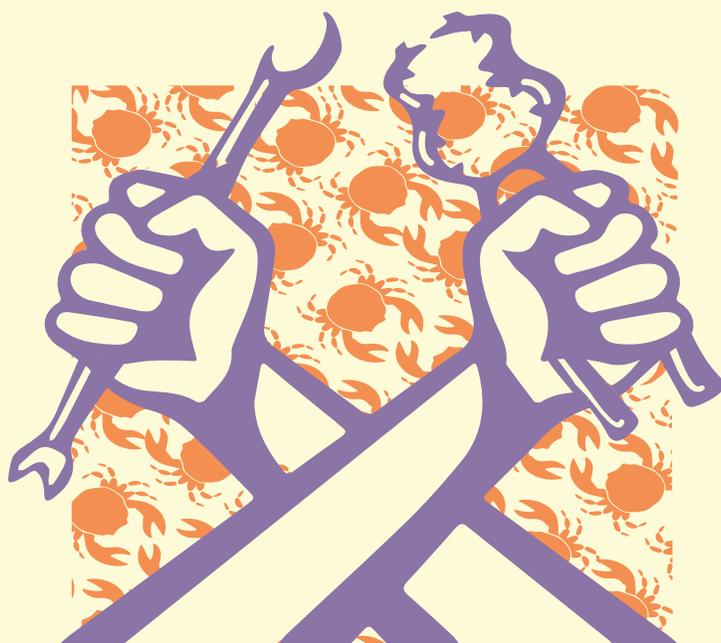
The
Hemophilia
Foundation of
Northern California

FOR ALL BLEEDING DISORDERS

Questions?

510-658-3324

ashley.gregory@hemofoundation.org



COMMUNITY CRAB FEED



Join us for our 14th annual Community Crab Feed complete with raffles and music. Our crab feed event brings supporters of the bleeding disorder community together for a fun-filled night complete with **all you can eat** pasta, bread, salad and crab.

This event supports the Hemophilia Foundation of Northern California's mission to serve the needs of people impacted by bleeding disorders through enhancing quality of life by providing support, education, outreach, advocacy and research through our affiliated national foundations.

Sunday, March 29th 2020

The Colombo Club
5321 Claremont Ave
Oakland, Ca 94618

Doors open 2:30pm
entertainment and town hall
meeting 3:00 - 4:00pm

Dinner served at 4:00pm
Music and dancing to follow

Get tickets online

Hemofoundation.org
or call (510) 658-3324

- All you can eat crab, salad and pasta
- Raffle and 50/50 drawing
- Live Music by Blue House
- No host bar

Tickets

Adult 13 and over	\$65
Kids 7-12	\$30
Child 6 and under	\$5
Table of 10	\$600



The
Hemophilia
Foundation of
Northern California

FOR ALL BLEEDING DISORDERS

Free Parking at DMV across the street from Colombo Club be very cautious crossing the street

this effort. Danny's Dose has established best practices for rare condition patients with self-carried, life saving medications and protocols. Darlene Shelton recommends the following:

- **Obtain EMERGENCY MEDICAL ORDERS from your specialist**
 - Must be on their letterhead, signed and dated annually
 - Must list an emergency on-call number
 - Must clearly state the patient's name
 - Must state emergency medication if applicable and dosage
 - Must outline steps to take in brief and precise format
- **For Medications: create an EMERGENCY MEDICINE - It should be clearly marked & always attached to the car-seat or an empty seatbelt in the car and should include:**
 - Emergency Medical Orders from your specialist
 - Emergency Treatment Plan from your EMS service
 - Emergency Dosage of your medication in the original packaging
 - Syringes, needles, tourniquets, etc needed to administer
 - Most current weight of the person

- **Contact your local Ambulance Service (both city and county if an option) Inform them of your special medical needs. Ask for a Treatment Plan to be created**

- This will only apply to that service but it's better than none
- Contact your local Hospital if you don't live near your Treatment Center
- Ask for an Emergency Treatment Plan there also
- Explain your special medical needs
- Ask how this plan will be utilized with changes in ER staff
- In many instances, hospitals will inform you that stabilizing and transporting is their only option but at least you will know to rely on the EMS staff. 🔥

Training is available for Hospital staff and Paramedics.

Contact Darlene Shelton at **1+573-820-2819** or darlene@dannysdose.com if you need assistance

Always have Personal & Auto Medical Alert

We have created Emergency Headrest Covers – which include a pocket for above items and two "Emergency & Medical Information Cards" \$12.00 per headrest.

For more information contact Darlene Shelton at darlene@dannysdose.com or call **1+573-820-2819**



COMMUNITY SPOTLIGHT: Shellye Horowitz

I am not incredibly religious, but I do consider myself spiritual. As such, I have often taken time to pause and reflect on the many gifts I have encountered on my life path. I will NEVER forget the weekend I spent in Santa Cruz at the second Female Factor retreat. While I grew up in a family with five generations of hemophilia, this was the first Hemophilia event I attended.

I am so thankful for HFNC for seeing the need to bring women together, and for The Female Factor community, who embraced me and planted seeds that would form deep roots and branch out to the greater hemophilia community. Not only did that first TFF retreat reinforce my growing understanding of the need for women to access hemophilia treatment, it also sparked a heart of advocacy.

Since the retreat, I have had the privilege of attending many hemophilia retreats, symposiums, trainings and conferences. Drawing from my background in counseling and education, I have led workshops for several Hemophilia chapters on a variety of topics and was honored to be able to address the women at the final session of the 2nd National Conference for Women with Hemophilia last November. Each experience gifts

me with more community connections. Stories shared by the women at events motivate me to continue to work for access to appropriate diagnosis and treatment for women in our community.

I currently write a weekly column for Hemophilia News Today titled, "The Forgotten Factor", which can be accessed online. I am able to use this platform as an opportunity to generate conversation on a variety of topics affecting women with bleeding disorders. These discussions have included patients, patient advocacy groups and medical providers. I have great hope that continued dialogue will shift the way women are treated when seeking care for their bleeding disorders.

In my freetime I am an avid geocacher (if you do not know what that is, I challenge you to look it up!) I am also a regular at our local international folk dance group and love spending time running my goldendoodle on the beach and hiking the many trails in our local forests.

It is a pleasure to be part of the HFNC community. You can follow me on Twitter or Instagram @HemoGirlsRock or find me on Facebook. 🔥

Familia de Sangre, 6-8 de Septiembre 2019, Anaheim



esta conferencia de habla hispana.

La conferencia comenzó el viernes por la noche con una sesión de apertura y comentarios del miembro de la Mesa Directiva de NHF, Jorge de la Riva. A una sala de exhibiciones emocionante la gente continuo bailando toda la noche con el DJ Stephen Skillz, y los adolescentes disfrutaron de su propio programa de trivia disco organizado por GutMonkey.

El sábado comenzó con deliciosas y atractivas sesiones de desayuno organizadas por los patrocinadores Takeda, Novo Nordisk y Sanofi Genzyme. Después del desayuno, los asistentes fueron educados a través de una variedad de sesiones educativas. Las parejas compartieron luchas y triunfos en sus relaciones en una sesión de asociación emocional, y los miembros de la comunidad estaban ansiosos por asistir a la sesión de terapia génica para conocer qué ensayos se están explorando.

Las sesiones informativas también incluyeron Inmigración, Terapias emergentes, así como dos sesiones de pie sobre los conceptos básicos de la marihuana medicinal. Los adolescentes quedaron cautivados por la increíble historia de Jhon Velasco y aprendieron cómo pueden combatir el estrés a través de las luchas cotidianas, y Pat Torrey de GutMonkey los tuvo a todos activos enseñándoles sobre cómo hacer cambios en la vida. Se compartieron historias personales y se derramaron lágrimas durante el panel de Culpa sin culpa para las madres mientras se conectaban con otras mujeres de la comunidad.

La noche terminó con los participantes disfrutando de boletos para Disneylandia. La sesión de clausura del domingo por la mañana fue una presentación importante de Takeda sobre

el 6 al 8 de Septiembre 2019, 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 organizaron la 3a Conferencia Anual de la Familia de Sangre en Anaheim, California. Más de 600 miembros de la comunidad asistieron a

la preparación para emergencias por desastres naturales, así como un sorteo de kits de emergencia.

Gracias a nuestro Equipo de la suite Médica del Hospital de Tratamiento Ortopédico, Doris Quon, MD, Directora Médica, y Christopher Chan, NP, por pasar su fin de semana de guardia en la conferencia, y gracias a Bayer por patrocinar nuestra suite Médica. Agradecemos a nuestros profesionales médicos de habla hispana por tomarse el tiempo para presentar: Erika Bocanegra, MSW, Daisy Cortes, MD, Vanessa Salinas, MD, Pedro Sanchez, MD, Claudio Sandoval, MD y Sandra Valdovinos-Heredia, MSW, ACSW. Agradecemos a la miembro de la mesa directiva de HFSC, Carol S. Jung, Esq. por ayudar en la presentación de temas escolares como los Planes 504 y los IEP.

¡Gracias a La Federación de Hemofilia de América y a la Fundación Nacional de Hemofilia por su asociación!

Agradecemos al patrocinador de titanio Takeda y a los presentadores de su equipo educativo de habla hispana: Clemencia Casas-Byots, Susana Escojido, RN, Binh Le, BS y Amalia Vega, MPH.

Nos gustaría agradecer a nuestros patrocinadores: los patrocinadores de platino Novo Nordisk y Sanofi Genzyme; Patrocinadores de oro Bayer, CSL Behring y Genentech; Patrocinadores de plata Octapharma y Brothers Healthcare. ¡Gracias a nuestros increíbles voluntarios! 🔥

GUARDAR LE FECHA DE FDS 2020! 18-20 de Septiembre 2020, Anaheim Marriott



"CLEAR EYES. OPEN EARS. FULL HEARTS. CAN'T LOSE!"

Taken from Friday Night Lights Coach Eric Taylor. "Open Ears" added by Dawn Pollard



What a year! Wonderful and terribly hard. Moving and frustrating. Questions and some answers. Learning that we need to keep asking questions. Changes, changes and more changes.

It was a very humbling year for me. As a retired pharmaceutical executive, a carrier from a family who lost two kids to hemophilia and a tireless, passionate volunteer and champion for Camp Hemotion and women, I learned a lot since getting involved. The unfortunate circumstances which led to me and another Board member steering the ship for a year also had a silver lining: I saw the Foundation from a different vantage point. I learned that HFNC is only a legal entity with no beating heart. I learned that the workload is brutal. I thought we might be missing resources. I learned that we were missing heart.

HFNC can only thrive with all of you supporting it! We can all do something that makes a difference. We understand that all of us are giving our time and energy and contributing financially to the extent we are able. When staff and volunteers work nights and weekends, we need to celebrate them. And we need to be open to input and changes. I want you to know that we are in a continuous learning mode and that won't stop.

We continue to make progress on the things you told us were important about your Foundation. Over 50 community members spent several evenings talking about the Vision and Values that you wanted to be reflected in our "new" organization.

The five most common themes we heard were:

1. Community first as a focus for all our activities. Lead with heart!
2. Make noise. Raise awareness about us. Educate us. Do it with heart!
3. Have leadership (not just ED) be visible and get to know us. Show us your hearts!
4. Lead our community with integrity, transparency, commitment and kindness! And expect the same from all of us!
5. Keep our entire bleeding disorders community together | while being sensitive to our individual bleeding disorders and cultural needs.

I talked about these things in our State of the Foundation update at our January 14, 2020 Community and Board meeting. I also pointed out the many good things we observed over the last year:

- The Board maintained the heart and soul of HFNC during a major, difficult transition.
- Hired an Executive Director from our community with a deep passion for our cause.
- Finished 2019 in the black! Not by much, but not in the red!
- Vine, Hops and Golf was financially successful.
- First ever Giving Tuesday Campaign raised over \$5,000
- Programs received great feedback

- Programs received great feedback
 - Crab Feed successfully returned
- – Camp Hemotion was extremely emotional
 - Female factor described as “life-changing” by attendees

Stanford to host Emerging Therapies Forum March 7

- Successful holiday parties
- Working more closely with all of our industry partners, including our manufacturers, our Specialty Pharmacies, our HTC’s and Kaiser.

Wow. That’s a lot! Kudos to all of you without whom these wonderful things would not have happened. We also had challenges. And it’s important that we talk about those also. Some of those include:

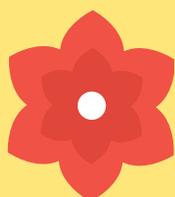
- Our Walk fell short of its goal.
- Our infrastructure needs rebuilding, including recreating policies and procedures lost during our transition
- Technology is challenging and our hardware and software are in dire shape
- A Board recruitment and succession plan is needed – our Board should be as diverse as our community!
- Recruitment for staff is very, very difficult in the highly competitive Bay Area.

- 2020 budget is not balanced.
- Attendance at events has been a challenge – needed for funding!
- Qualified Spanish-speaking staff member not yet found despite aggressive recruiting

So in the face of challenges, I am grateful for the true good our Foundation does for our community. And I want to end this the way I started: “Clear eyes. Open Ears. Full Hearts. Can’t Lose.” And with a heartfelt thank you to everyone in the community and the Board and HFNC staff for teaching me so much. By you doing what you do, I get more comfort than you can imagine knowing that my brothers’ deaths were not in vain. That doing good for others is the best way to mend a broken heart. With warmth and gratitude. 🔥

Dawn Pollard, *Board President*

UPCOMING EVENTS



ASIAN
INFUSION
2020

SAVE THE DATE
SUNDAY, FEBRUARY 23, 2020

星期日，2月23號2020年 敬請留意

MĀLAMA I KA LĀ LĀPULE, PEPELUALI 23, 2020

HUWAG KALIMUTIN ANG PETA SA LINGGO,
IKA23, FEBRERO, 2020

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EMERGING THERAPIES FORUM

7 de marzo | March 7, 2020



The
Hemophilia
Foundation of
Northern California

FOR ALL BLEEDING DISORDERS

Stanford University
9:00am - 4:00pm
Frances Arrillaga Alumni Center
326 Galvez St.
Stanford, CA 94305

Learn about novel therapies in bleeding disorders such as subcutaneous injection, gene therapy, and more!

- Breakfast and lunch provided
- Exhibit hall
- Childcare available
- *Receive tickets to Great America

*Attendees will receive ticket via mail upon processing of completed passport from event. Some restrictions may apply.

Register at www.hemofoundation.org or call 510-658-3324

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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
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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

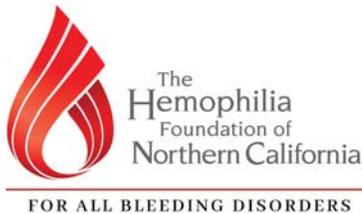


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Since we do not engage in the practice of medicine, we always recommend that you consult a physician before pursuing any course of treatment.

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