

INFUSIONS

NEWSLETTER OF THE HEMOPHILIA FOUNDATION OF NORTHERN CALIFORNIA • FALL 2019

Newly Implemented Advocacy Program Taking Off



By Ashley Gregory, HFNC Education & Advocacy Director

Emeryville, California

Have you ever wondered what advocacy means? Webster's Dictionary defines it as "the act or process of supporting a cause or proposal." HFNC is partnering with our national organizations and with you, our community, on an advocacy project to help people recognize signs and symptoms of undiagnosed bleeding disorders and to

raise awareness. This is how we can ensure access to diagnosis and treatment for all individuals with a bleeding disorder.

According to the CDC, 10% of the population has an undiagnosed bleeding disorder. Many bleeding disorders are genetic, like von Willebrand's Disease and Hemophilia, but some are not genetically linked, like Hemophilia C (Acquired Hemophilia).

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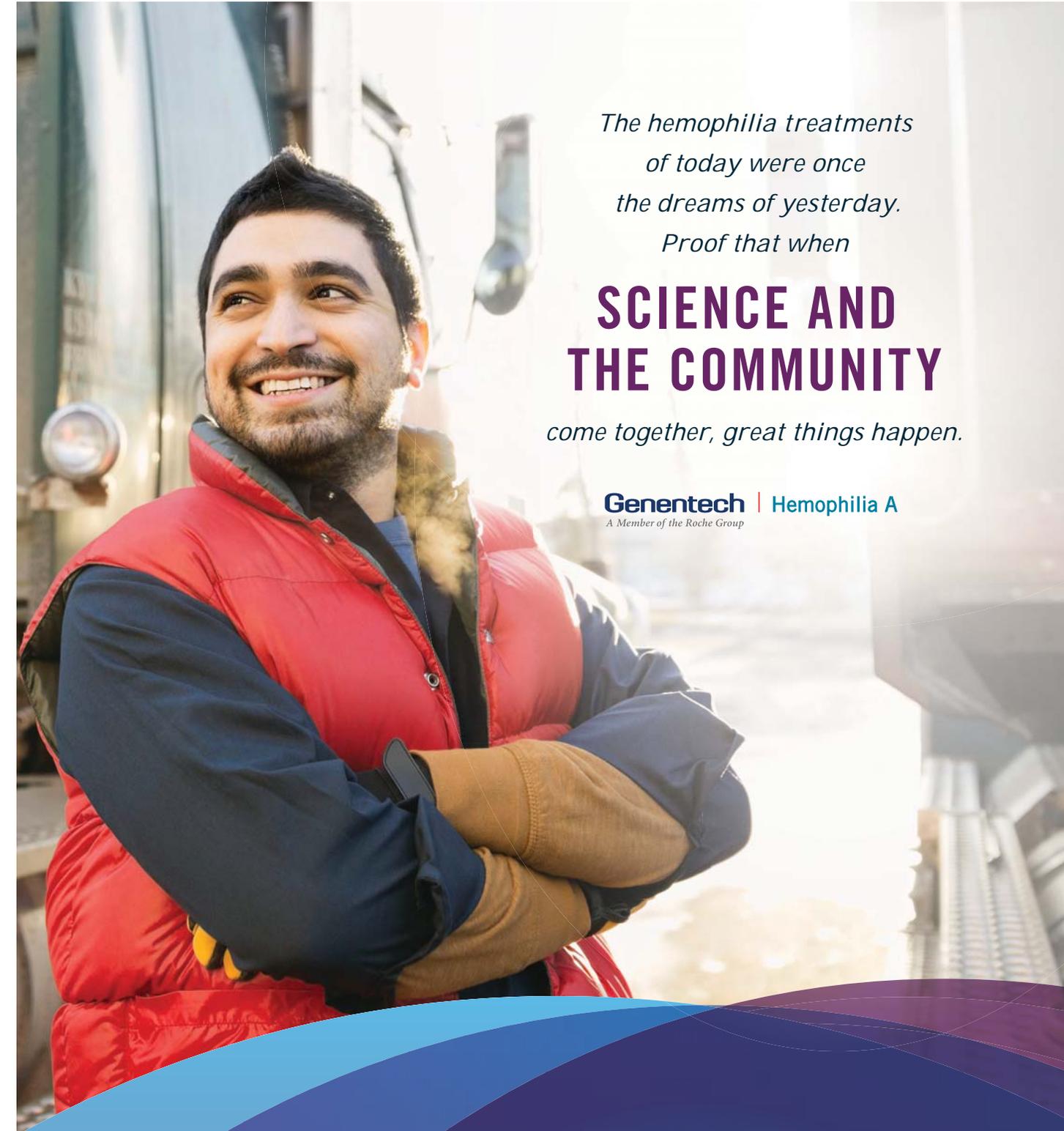


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*The hemophilia treatments
of today were once
the dreams of yesterday.
Proof that when*

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come together, great things happen.

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Let's put science to work

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HFNC's Female Factor Retreat is a unique and unifying experience for women across the nation! Read two individual experiences here and contact Ashley Gregory at ashley.gregory@hemofoundation.org if you'd like to attend The Female Factor 6th Annual Retreat in October 2020!

Grateful and Changed by The Female Factor Retreat

By Dawn Litchey

October 2019, New Jersey

My name is Dawn Litchey, I am affected by Hemophilia. I am a Mom and a symptomatic carrier of Severe Hemophilia A.

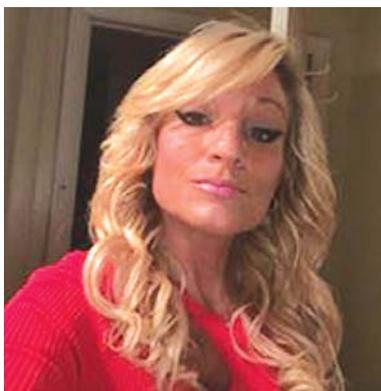
To give you a little background of my life, I was born into the hemophilia world as I had one brother seven years older than I that was afflicted by Severe Hemophilia A. I myself gave birth to six sons, four of which had Severe Hemophilia A. Hemophilia and/or bleeding disorders affects your whole life; who you are and who you become, and with myself, what I do for a living, and my life's purpose.

Back in 1981, when my first son Christopher was born, there was no support, no help, no awareness, and no education. There were no support groups around, no computers, no social media. When your child (children) were born you felt so alone. Hemophiliacs didn't receive support, no one offered education.

I myself was a young Mom of 18 living in Northeast PA. I spent those days in ER's every time my children bled, which was often. This IS a life threatening disorder. Education?? I spent long days in hospital medical libraries researching any information I could find on Hemophilia so I could educate myself. I needed to be informed to protect and care for my children. After all, the encyclopedia had maybe two sentences explaining the disorder. Women were all classified as symptomatic carriers when WE had so many bleeding issues ourselves. We were dismissed, ignored, put to the side. My children's ages range from 38 down to 13. I've lived and experienced many decades of this. Two of my beautiful sons have died due to Hemophilia related causes:

Christopher 11/26/81-2/2/2000. Adam 12/29/94-7/3/2015.

The bleeding disorder community was a dark secret place. A place that you silently suffered - alone. No one understood or accepted us. Then in the 80's AIDS came into the picture. Most hemophiliacs in the 80's became HIV infected through the clotting factor medication they injected to treat their bleeding disorder. My brother and my oldest son included. My brother Mike passed away in 2005.



We were afraid and alone. The pain, depression, loneliness and isolation I've faced over the years was often more than I could bear and I'm a strong woman! It nearly took my own life more than once. It was an era where we were hurting, we were wounded, we were tired, depressed and worn, but we needed to go on for the lives of our children, partners, spouses, family, friends, loved ones and ourselves. Women like myself had bleeding issues our whole lives. We bled unusually - yet we had no voice, no care and what we once thought, no hope!

Through the years, I'm so grateful and proud to say things are changing. But how do we get support, love and attention to our cause? Our community? I myself took what happened to me in my own life and turned it around to help others and so did many others. WE ARE STRONG!!!

Last weekend I had the opportunity to attend the Female Factor 5th Annual Retreat in Monterey, California. The Female Factor is a group of women that are affected and connected and is a program that is foundation run and operated.

After my second son Adam passed in 2015, I slipped into a severe depression. I withdrew, isolated myself, to be honest with you, I didn't want to live. I went for every type of therapy there was for years. Yet, no one understood, I was still alone. I eventually lost everything I owned and felt I had nowhere to turn. Depressed, alone, broken and ashamed of myself because I knew "I wasn't right" and felt weak and full of failure. I beat myself up and slipped back even further. I blamed myself. This is not uncommon in the bleeding disorder community. At the bottom again, alone and afraid, I decided with the help of God to stand once again. With very weak knees and a timid heart I reached out. I found a job with an amazing Specialty Pharmacy again, Paragon Healthcare. They began to help me grow again, they supported me, the "whole" me. I started reaching out to the community again, sharing, loving...living again! I had spent 19 years working in this community, more volunteering and my whole life living in it. I joined the Female Factor Group through my friend Ashley

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Grateful *Continued from Page 3*

Gregory. She brought to my attention about the Female Factor Retreat in Monterey. I contacted her, she explained women come from all over the US and abroad attend. "It's amazing," she said. "Come ". I approached the company I work for. I knew they believe in wellness and wholeness, I asked, "Will you help me attend "? Yes, they said!! This will be good for you and not only that, they included my dear friend and coworker Stormy Johnson from Atlanta, GA. I live in NJ. She has Hemophilia B and so does her son. This was about us, not just Stormy and I, but about all women! I had never gone to a "retreat", I didn't know what to expect. Upon arrival to the retreat, my life was forever changed. I AM STRONGER... I AM BETTER because of it. Upon registration we received bags that read, "When women support each other... incredible things happen "! They couldn't have been more right!!! Women came from all over, suddenly I felt more supported and stronger than I had in years. We bonded, we shared, we loved, we cared. We have a voice! We connected and will forever be connected. One weekend added so much to my life, I cannot ever explain.

The retreat was on the beach, our view was the rolling ocean. It was beautiful. Activities were set up to enjoy. We did yoga, crafts,

played games, got amazing education, had time to bond, be together, speak with uninhibited voices, learn, share and grow together!!! I can't begin to tell you about all the beautiful and amazing women that I met. I cannot tell you how many times I laughed, cried, shared, listened, learned, loved and how this enriched my life. The Educational programs were amazing and informative. I learned so much. Not just slides and presentations, it was real life issues, medical, useful information and openness. Sharing our stories and ourselves. It was medical information, wellness, wholeness and we ALL became stronger because of it. The support? I never experienced anything like it. The love??? Wow, it was there!!! We were all touched, you could feel it. It was magical!!!

We are women, we are strong. We need to be heard. We bleed, we suffer, we need to be recognized, taken seriously.

I am forever changed in so many positive ways because of that weekend. I am grateful... I am loved!!

WE ARE WOMEN! WE ARE STRONG! WE HAVE BONDED!! WE WILL BE HEARD! WE MATTER!!! 🔥

Shared Experiences Nurture Emotional Connections

By Sarah Chan



October, 2019 San Francisco, CA

I attended the fifth annual Female Factor retreat hosted by the Hemophilia Foundation of Northern California. This was my second year attending this event. It was a weekend filled with education, empathy, and empowerment. Not only did we learn more about the unique challenges we face as women affected by bleeding disorders, we also learned strategies to help take better care of ourselves both mentally and physically. Aside from learning more about being a woman with a bleeding disorder, speakers at the event led sessions on topics such as self advocacy, genetic counseling, parenting with a chronic illness, and mindfulness. These talks were balanced with activities which included yoga, rock painting, and a beach bonfire.

My favorite part about the bleeding disorder education that goes on at this event is the fact that it encompasses all bleeding disorders. As a woman with a rare platelet function disorder, sometimes it's hard to find my place within the greater bleeding disorders community. I struggle with feeling like talks about

specific bleeding disorders don't apply to me and often feel disheartened. At this event, the focus is on the unique challenges we face as women with a bleeding disorder rather than a specific diagnosis (that one may or may not have). This sentiment was echoed in other sessions throughout the weekend.

The most beneficial part of these kinds of events is the ability to share our experiences and learn from the experiences of others. As the event brought together women from across California (and across the country), we shared tips and tricks that we've picked up over the years. Events like these are a unique opportunity not only to get educated about the nuances of life with a bleeding disorder but also to nurture emotional connections with others in similar situations. Since the community of women with bleeding disorders is so small, it's crucial that we share not only what's worked for us but furthermore what could still use updating or improvement.

I look forward to seeing where the sixth annual Female Factor retreat brings in 2020.

Thanks for all you do for us!-Sarah 🔥

Advocacy Program *Continued from Page 1*

Each of these variations may cause symptoms that can lead to pain, social stigma, lower productivity, and lower quality of life. Since these conditions are rare, recognizing the symptoms can be difficult due to lack of knowledge on the part of medical providers and the general public.

Visits with a medical provider can be challenging when trying to determine if symptoms are bleeding disorder related. The National Hemophilia Foundation has published an online symptom assessor tool called BetterYouKnow.org. Taking this assessment can help determine if puzzling symptoms are bleeding disorder related. People can share the results with their care provider for a referral to a specialist that can help, called a hematologist. It is important to be evaluated by a *benign* hematologist since many hematologists focus on oncology. A *benign* hematologist specializes in bleeding disorders, which can be difficult to diagnose, especially in women and mild cases. Many benign hematologists are found at federally designated Hemophilia Treatment Centers (HTC's) across the U.S. There are five HTCs in Northern California. Using tools like BetterYouKnow.org can assist in sharing concerns with a medical provider.

In addition, raising awareness in our local communities and among local government officials can ensure better access to care and treatment. Nationally, March was declared Hemophilia Awareness Month in 1986 by President Ronald Reagan, yet most local municipalities have not followed suit. Until now! On April 12, 2019, HFNC and the City of Santa Cruz partnered with Mayor Martine Watkins to have March declared Bleeding Disorders Awareness Month.

You can raise awareness in your local community by using and sharing tools like BetterYouKnow.org, and by advocating for a Proclamation similar to the one in our picture from your own municipality or township. HFNC's local Advocacy Program

helps train community members to become advocates at the local level, including meeting with government officials and obtaining an official proclamation.

If you are interested in becoming a part of this project, please contact Ashley Gregory at ashley.gregory@hemofoundation.org. 

DO THE FIVE

What are the "Do the Five" steps?

- 

Have an annual checkup at a Hemophilia Treatment Center (HTC).

 - Receiving care at an HTC improves overall health and well-being.
- 

Get vaccinated.

 - Hepatitis A and hepatitis B are preventable!
- 

Treat bleeds early and adequately to help prevent long-term damage.

 - Centers for Disease Control and Prevention (CDC) and the National Hemophilia Foundation (NHF) recommend treating a bleed within one hour.
- 

Exercise and maintain a healthy body weight.

 - Exercise strengthens your muscles strong muscles help protect your joints.
- 

Get tested regularly for bloodborne infections.

 - Blood products are safer than ever; keeping a watchful eye on them helps ensure continued safety.

CALENDAR

January 1, 2020	New Years Day	
January 14, 2020	Board Meeting In Person, HFNC Office/call in 510-972-9851	HFNC
January 16-19, 2020	NACCHO, Phoenix, AZ	NHF
January 17-19, 2020	Family Camp, Camp Arroyo, Livermore, CA	HFNC
January 25, 2020	Board Retreat, TBD	HFNC
February 11, 2020	Board Meeting Call In, 510-972-9851	HFNC
February 17, 2020	President's Day	
February 23, 2020	Asian Infusion, TBD	HFNC
February 26-28, 2020	NHF's Washington Days, Washington DC	NHF
February 28, 2020	Rare Disease Day	
March 1-31, 2020	Bleeding Disorder Awareness Month, Local cities in California	HFNC
March 7, 2020	Emerging Therapies Forum, Stanford University	HFNC
March 9-12, 2020	Chapter Leadership, Dallas, TX	NHF
March 10, 2020	Board Meeting In Person, HFNC Office/Call In 510-972-9851	HFNC
March 29, 2020	Annual Meeting and Community Crab Feed, Columbo Club	HFNC
April 2-5, 2020	YETI Conference	
April 4-6, 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	
April 23-26, 2020	HFA Symposium, Baltimore, MD	HFA
TBD	Future Leaders/LEG Day, Sacramento, CA	HCC
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 13-14, 2020	2020 Camp Hemotion Staff and Counselor Training Camp Oakhurst, Coarsegold, CA	HFNC
June 14-20, 2020	Camp Hemotion, Camp Oakhurst, Coarsegold, CA	HFNC
June 14-17, 2020	World Hemophilia Congress, Kuala Lumpur	WFH
June 27, 2020	Vines & Hops Silent Auction, Wine & Beer Tasting, TBD	HFNC

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.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/>

Community Spotlight: Laura Schulte Walters



Nevada City, California

I originally learned how to make macramé keychains at hemophilia camp.

I just kept practicing after my last year as a camper and made them for my friends in high school sometimes. I will make them for my friends based off what is requested, but sometimes I will do matching ones.

I started knitting as a hobby in 2015, and as a way to connect, I would sometimes ask my hemo family questions about their favorite colors, do they wear hats or scarves, etc.. Their answers gave me various options to work with if I decided on making a gift.

I added the recipe books in 2016 when I began subtly asking about preferences, likes, dislikes, specific courses, cuisines, or dishes.

I am careful to avoid any allergy or intolerance issues and I base the recipe book itself off preferences, likes, and specificities (i.e. appetizers, desserts, or even cuisines).

I am inspired to connect with my hemo/blood family this way because of the thought, time, and effort put into each gift. It is very rare to see homemade or handmade gifts anymore so to me, those have a more powerful impact and meaning. I think each gift shows the dedication, love, time and effort that was invested. Each recipient has a different reaction when receiving their gift too. 🔥

Connect with Laura Schulte Walters via Facebook
[@facebook.com/lmuchihha](https://www.facebook.com/lmuchihha)

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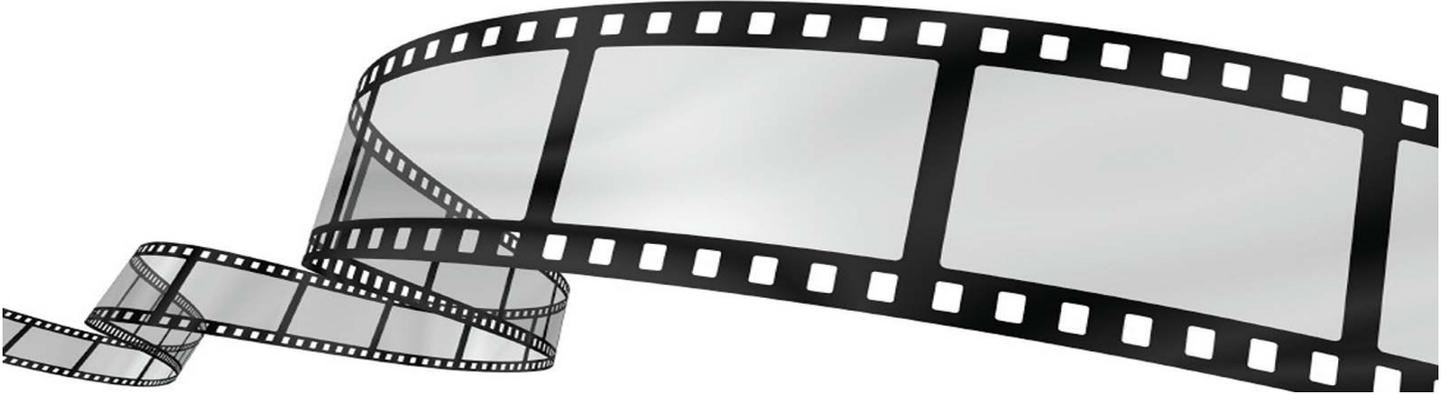
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Jivi
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LET'S GO

Casting Call From Believe Limited



Believe Limited (believeltd.com) is casting for its next video series and is looking for several community members who would be interested in telling their story on camera. This video series is meant to highlight the unique struggle of the workplace when you are affected by hemophilia. Believe is looking for stories of inspiration as well as stories of struggle and frustration while trying to follow a passion or just looking for work. The project is funded by a pharmaceutical company and participants will be compensated for their time.

Who Should Apply:

Hemophilia patients/caregivers that have a story about their work life that fit into one of the following 5 categories:

Struggling. Are you struggling or a little lost finding your place in a work environment? Maybe you need help finding a job or don't know what to do with your life. Maybe you are trying to change jobs and it's not going well.

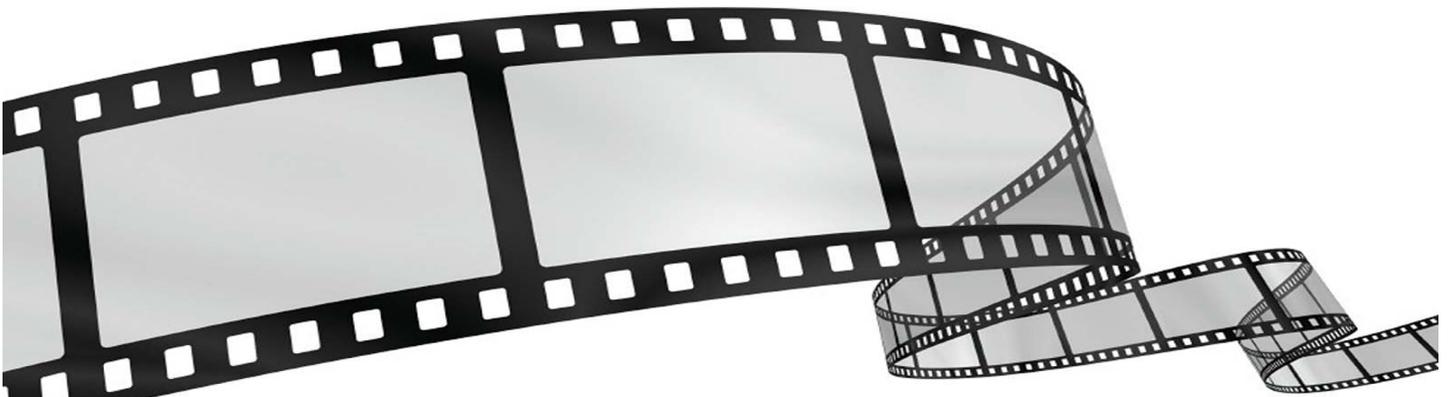
Thriving. Do you have a notable or distinguished career that you are proud of? Did you overcome adversity and could be an inspiration for other hemophilia A patients?

Adapting. Have you adapted your outlook on career to account for both passion and hemophilia? Maybe you felt limited because your passion didn't align with taking care of yourself and your hemophilia, but you were able to adapt your career to include both.

Recovering. Are you someone who's professional life has been interesting, colorful; maybe remarkable, maybe more ordinary, but a recent surgery/operation/medical complication has forced you to slow down and recover first. Maybe you are trying to find the balance within the process of recovery and reinvention.

Identifying. Are you a caregiver who had a robust professional life before parenthood, including hemophilia care? Now you are ready to reenter the professional world and struggle with wondering if parenthood and hemophilia has impacted your professional value.

To apply, please contact Amy Board, Director of Innovation at Believe Ltd, amy@believeltd.com. 



Dear HFNC Community Members:



I recently attended NHF's Unite Walk Rally in San Antonio during which chapters from all over the country received training and support for our Walk programs. At one point, we were asked to create a short 30 second video answering the question "Why do I do what I do?" So here's my answer:

I do what I do because I care about my brother. I want to make sure that even though treatments have dramatically improved since he was a little boy, that he always has access to safe and affordable care. I do what I do because I care about my coworkers and friends who have lost family members as a result of Hemophilia. For them, the HFNC community provides support and allows them to honor the memory of their loved ones. I do what I do because of the women who have symptoms of a bleeding

disorder but struggle to obtain treatment. I do this because of the parents who are terrified when they find out that their child is different, and I do it so that if I am ever that parent I will have a support system as well.

There was a volunteer from the Oregon chapter at the Walk Rally who got up and told us all why she volunteers even though her son is well cared for and they have adequate finances. She said it was an investment in his future, to be able to know that if that need should ever arise that there would be a strong Foundation in place to fight for her and her family. It is my hope that HFNC can be that for all of you.

Thank you for allowing me to be of service to this community,
Alona Metz, Executive Director 

Danielle Mueller Durham

Patient advocate

About Danielle

Danielle is a Hemophilia Community Liaison who has been supporting the bleeding disorders community for 8 years. She works hard to make sure everyone in the community has a voice and knows how to ask for what they need.

Connect with Danielle

DIDH@novonordisk.com
(206) 316-0748



Hemophilia Community Liaison

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Eureka Gathering

By Shellye Horowitz

Eureka, California

On December 5, 2019 a group of over 20 people gathered in Eureka, California to learn about empowerment, network and support each other as individuals affected by and connected to hemophilia in a rural community. Many participants commented that they thought they were alone. They did not know there were other families hidden in our rural community who were also struggling with the unique reality of managing hemophilia while living so far away from their treatment center and other affected families.

Participants shared their excitement to form networks and expressed their desire to see future local programming on a variety of topics from joint health to women with bleeding disorders. Additionally, some attendees discussed ways to network with local

officials to assure improved treatment protocols for people with hemophilia in our rural community.

We are so thankful to HFNC, and Leslie Ferber and Sanofi-Genzyme for helping gather our local community for the first time. We look forward to future HFNC sponsored events and our continued personal connections with each other. 

**Note: If you are an Industry partner and would like to schedule Food for Thought programs in 2020, please contact ashley.gregory@hemofoundation.org and we will gladly set a time to talk. Thank you to all our Industry partners this year for supporting local, grassroots education that allows families and patients to gather and grow as a community.*



My Experience at Family Education Day 2019

By Maria Barraza

November 2019, San Jose, California

What a great experience we had at Family Education Day!! The Mental Health First Aid session was something I was most excited about. Talking to other people about feelings that not many can understand without being judged is PRICELESS. My overall FAVORITE part was having Patrick James Lynch be a part of it by bringing the movie, *Bombardier Blood!* What an amazing movie; I cried, realizing that my son was not alone in his struggles with dealing with hemophilia and seeing what Chris Bombardier has accomplished gave me so much hope for my kids' future!! "Thank you HFNC for an incredible night." 





Thank you to all that donated to our
Giving Tuesday Campaign!

We raised **\$4,669.00** so our community members and their
families could experience the joy of the season!

We wish to extend a SPECIAL thank you to our top fundraisers

Dawn Pollard

&

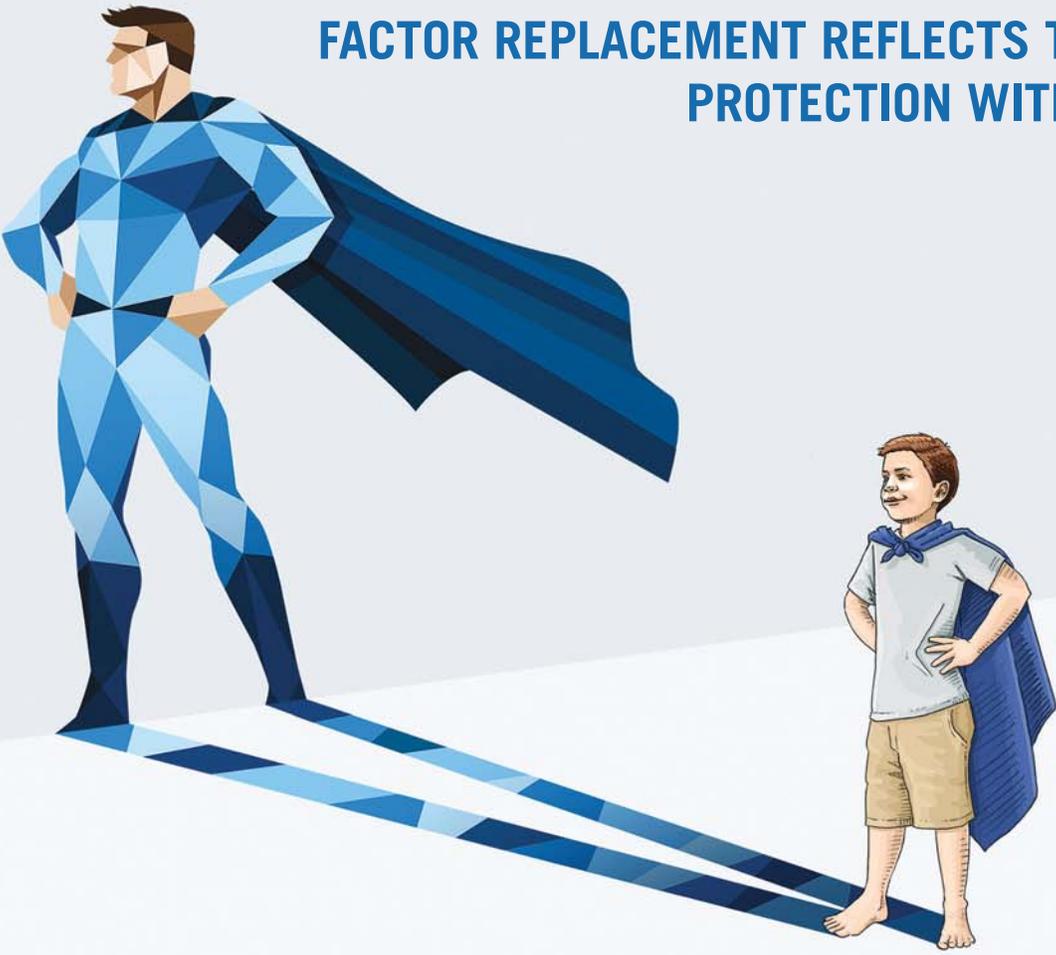


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HFNC's Posada Navidena committee and volunteers celebrate with Santa





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References: **1.** Peyvandi F, Garagiola I, Young G. The past and future of haemophilia: diagnosis, treatments, and its complications. *Lancet*. 2016;388:187-197. **2.** Canadian Hemophilia Society. Factor replacement therapy. <http://www.hemophilia.ca/en/bleeding-disorders/hemophilia-a-and-b/the-treatment-of-hemophilia/factor-replacement-therapy/>. Accessed May 18, 2018. **3.** Franchini M, Mannucci PM. The history of hemophilia. *Semin Thromb Hemost*. 2014;40:571-576. **4.** Hvas AM, Sørensen HT, Norengaard L, Christiansen K, Ingerslev J, Sørensen B. Tranexamic acid combined with recombinant factor VIII increases clot resistance to accelerated fibrinolysis in severe hemophilia A. *J Thromb Haemost*. 2007;5:2408-2414. **5.** Antovic A, Mikovic D, Elezovic I, Zabczyk M, Huttenby K, Antovic JP. Improvement of fibrin clot structure after factor VIII injection in haemophilia A patients treated on demand. *Thromb Haemost*. 2014;111(4):656-661. **6.** Berg JM, Tymoczko JL, Stryer L. Many enzymes are activated by specific proteolytic cleavage. In: *Biochemistry*. 5th ed. New York, NY: WH Freeman; 2002. <https://www.ncbi.nlm.nih.gov/books/NBK22589/>. Accessed May 18, 2018. **7.** Shire. Shire's 70+ year commitment to the hemophilia community. <https://www.shire.com/en/newsroom/2018/january/7sosj>. Accessed June 6, 2018.

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UPCOMING EVENTS




Family Camp 2020

SIGN UP TODAY!

JANUARY 17-19 **Camp Arroyo**
Livermore, CA
Register at www.hemofoundation.org

Camp Donor Taylor Family FOUNDATION




FOR ALL BLEEDING DISORDERS



ASIAN INFUSION 2020

SAVE THE DATE
SUNDAY, FEBRUARY 23, 2020

星期日，2月23號2020年
敬請留意



RESERVE LA FECHA | SAVE THE DATE

EMERGING THERAPIES FORUM

7 de marzo | March 7, 2020
Stanford University



The Hemophilia Foundation of Northern California

FOR ALL BLEEDING DISORDERS



FOR ALL BLEEDING DISORDERS

14TH ANNUAL

Community Crab Feed

SAVE THE DATE

Sunday,
March 29, 2020



Colombo Club
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RIXUBIS® [Coagulation Factor IX (Recombinant)] Important Information

What is RIXUBIS?

RIXUBIS is an injectable medicine used to replace clotting factor IX that is missing in adults and children with hemophilia B (also called congenital factor IX deficiency or Christmas disease).

RIXUBIS is used to control and prevent bleeding in people with hemophilia B. Your healthcare provider may give you RIXUBIS when you have surgery. RIXUBIS can reduce the number of bleeding episodes when used regularly (prophylaxis).

Detailed Important Risk Information for RIXUBIS® [Coagulation Factor IX (Recombinant)]

Who should not use RIXUBIS?

You should not use RIXUBIS if you

- are allergic to hamsters
- are allergic to any ingredients in RIXUBIS.

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

What should I tell my healthcare provider before using RIXUBIS?

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 hamsters

What should I tell my healthcare provider before using RIXUBIS? (cont'd)

- are breastfeeding. It is not known if RIXUBIS passes into your milk and if it can harm your baby
- are pregnant or planning to become pregnant. It is not known if RIXUBIS may harm your unborn baby
- have been told that you have inhibitors to factor IX (because RIXUBIS may not work for you).

What are the possible side effects of RIXUBIS?

Allergic reactions may occur with RIXUBIS. Call your healthcare provider or get emergency treatment right away if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea, or fainting. Some common side effects of RIXUBIS were unusual taste in the mouth and limb pain.

Tell your healthcare provider about any side effects that bother you or do not go away.

What else should I know about RIXUBIS?

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

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 RIXUBIS Important Facts on the following page and talk to your healthcare provider.



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[COAGULATION FACTOR IX
(RECOMBINANT)]

MOVING FORWARD

Important facts about RIXUBIS®:

This leaflet summarizes important information about RIXUBIS. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider.

RIXUBIS
[COAGULATION FACTOR IX
(RECOMBINANT)]

What is RIXUBIS used for?

RIXUBIS is a medicine used to replace clotting factor (Factor IX) that is missing in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Hemophilia B is an inherited bleeding disorder that prevents blood from clotting normally. RIXUBIS is used to prevent and control bleeding in people with hemophilia B. Your healthcare provider may give you RIXUBIS when you have surgery. RIXUBIS can reduce the number of bleeding episodes when used regularly (prophylaxis).

Who should not use RIXUBIS?

You should not use RIXUBIS if you

- are allergic to hamsters
- are allergic to any ingredients in RIXUBIS.

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

What should I tell my healthcare provider before using RIXUBIS?

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 hamsters
- are breastfeeding. It is not known if RIXUBIS passes into your milk and if it can harm your baby
- are pregnant or planning to become pregnant. It is not known if RIXUBIS may harm your unborn baby
- have been told that you have inhibitors to factor IX (because RIXUBIS may not work for you).

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

Allergic reactions have been reported with RIXUBIS. Stop using the product and call your healthcare provider or get emergency treatment right away if you get a rash or hives; rapid swelling of the skin or mucous membranes; itching; tightness of the throat; chest pain or tightness; wheezing; difficulty breathing; low blood pressure; lightheadedness; dizziness; nausea; vomiting; tingling, prickling, burning, or numbness of the skin; restlessness; or fainting.

Your body may form inhibitors to factor IX. An inhibitor is part of the body's defense system. If you form inhibitors, it may stop RIXUBIS 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 IX.

The use of factor IX containing products has been associated with the development of blood clots. Talk to your doctor about your risk for potential complications and whether RIXUBIS is right for you.

What are the possible side effects of RIXUBIS?

Some common side effects of RIXUBIS were unusual taste in the mouth, limb pain, and atypical blood test results. Tell your healthcare provider about any side effects that bother you or do not go away. These are not all the side effects possible with RIXUBIS. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about RIXUBIS?

Consult with your healthcare provider to make sure your factor IX activity blood levels are monitored so they are right for you.

You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia B learn to infuse their RIXUBIS by themselves or with the help of a family member.

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

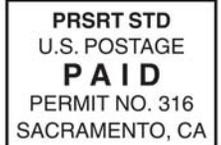
Medicines are sometimes prescribed for purposes other than those listed here. Do not use RIXUBIS for a condition for which it is not prescribed. Do not share RIXUBIS with other people, even if they have the same symptoms that you have.

The risk information provided here is not comprehensive. To learn more, talk about RIXUBIS with your healthcare provider or pharmacist. The FDA-approved product labeling can be found at https://www.shirecontent.com/PI/PDFs/RIXUBIS_USA_ENG.pdf or by calling 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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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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