SPRING 2023

Infusions

The Hemophilia Foundation of Northern California

FOR ALL BLEEDING DISORDERS

REGISTRATION IS OPEN!

CAMP HEMOTION

JUNE 25 - JULY 1

REGISTER NOW

USE CODE **HEMOZERO** IF UNABLE TO PAY

AGES 7-14 CAMPERS

AGES 15-17 JUNIOR COUNSELORS

AGES 18 - 20 ASSISTANT COUNSELORS

AGES 21 & UP ADULT COUNSELORS

HEMOFOUNDATION.ORG/EVENTS

QUESTIONS? 510-658-3324 | PEDRO.PRECIADO@HEMOFOUNDATION.ORG

Register HERE

Aim your camera at this QR code

IN THIS ISSUE

HEMOPHILIA FOUNDATION OF NORTHERN CALIFORNIA

Left to right: Zuiho Taniguchi, Randy Curtis, Pete Barbounis, Andrea Orozco, Mosi Williams, Michael Bradley, Anita Bawa, Dawn Pollard, Derek Sim

Meet YOUR Board of Directors

Hemophilia Foundation of Northern California Board Members

Randy Curtis - Board President - Past Board Member. Bleeding disorders advocate for the last 40 years. Person born with hemophilia.

Dawn Pollard - Vice President & former Board of Directors President - Over 30 years in biotech human resources. Sibling of two brothers with hemophilia and diagnosed carrier.

Derek Sim – Secretary - Scientist involved in drug development for hematological disorders for the last 20 years, including experience in developing hemophilia therapies.

Anita Bawa - Treasurer - Over 25 years experience in blood banking, biotech manufacturing, cell and gene therapy and previously worked on factor VIII products.

Marion Koerper, M.D. – Founder and past director for the UCSF Hemophilia Treatment Center for 56 years. Past Medical director for Camp Hemotion and past Vice Chair of the National Hemophilia Foundation's Medical and Scientific Advisory Council (MASAC).

Pete Barbounis - Board member for seven plus years and previous Board of Directors Vice President. Camp Hemotion counselor and chair of the annual charity golf tournament. Note: Pete has since resigned. We are incredibly grateful for his service.

Michael Bradley - Involved in bleeding disorders for over 35 years as a member of HTC team, industry executive, HCC board president, and current rare disease consultant.

Mark Helm - Active in Fresno area hemophilia auxiliary activities for 25 years. Pharmacy owner for 33 years. Currently a farmer/rancher in Sanger, CA. Person with hemophilia as well as father of a 30 year old son with hemophilia.

Tony Materna - Past Board member, former biotech CEO, worked on genetic repair of hemophilia. Serial entrepreneur for the last 35 years. Note: Tony has since resigned. We are incredibly grateful for his service and look forward to his continuing involvement on our committees.

Bob Seaton- Board member for the past six years. Executive in the medical industry and small business owner. Note: Bob has since resigned. We are incredibly grateful for his service.

Zuiho Taniguchi - Current Co-Director for Camp Hemotion as well as past board member 15 years ago.

Mosi Williams - Board member since 2021. Board member for the Hemophilia Council of California. Camp Hemotion JC/AC co-Coordinator. UCSF Adult HTC Social Worker.

NOTE FROM HFNC'S BOARD PRESIDENT

Now that I have retired, I would like to bring my past experience on other boards (Hemophilia Council of California, Center for Inherited Blood Disorders and Hemophilia Foundation of Northern California) to bear on the challenges and opportunities we have in the current environment. As we prepare to get back to meeting in person, we need to address the needs of the entire community including women with bleeding disorders, the Latino community and helping families of all kinds adjust to lives with a bleeding condition. - Randy Curtis, Jan '23

The Board of Directors used to be elected by dues paying members of the Foundation. Membership dues have gone away as well as the annual meetings where the voting occurred. The Board of Directors now accepts applications from community members that submit a letter of intent. This letter contains a description of their relevant experience and a statement of their reason for wanting to serve.

Board members are elected to a two year term that can be renewed once for a total of four years in any position. The Board suspended term limits during the early days of COVID and Dawn Pollard had served more than four years as president and had asked Randy Curtis if he would be willing to serve. Randy has a lot of experience on many boards and submitted his letter of intent. He was accepted to the Board on October 11, 2022 and elected president on December 14, with a start date of January 1, 2023.

The bylaws only states "Directors shall be members in good standing." In reality we screen all Board members for any potential conflict of interest (e.g. employment by a specialty pharmacy). This would potentially give the director access to the foundation mailing list. We also look for specific skills that would help us support the community. Currently, we are looking for new members of the board of directors that are bi-lingual in Spanish to help us grow our Latino offerings.

Please contact HFNC to be put in touch with Randy or Dawn to discuss serving on the HFNC Board of Directors.

510-658-3324 infohfnc@hemofoundation.org hemofoundaion.org/support/volunteer

ASK THE DOC

MARION KOERPER, M.D.
MEDICAL ADVISOR, HFNC

Q: Do I need to wear a mask? Why?
A: There are currently three potentially deadly respiratory viruses circulating in Northern California; these include COVID and its variants, flu, and RSV.
These viruses are spread by breathing in droplets containing them in the air. Wearing a mask can prevent this.

Q: When should I wear one?
A: Whenever you are in a closed space with people you don't know and who are not wearing a mask.

Q: How long will I need to wear a mask?
A. Until the risk from COVID and its variants is over. This may be next year. Covid will probably always be a threat in the winter like flu is.

Q: What else can I do to protect myself?
A1. Get vaccinated against COVID.
A2. Get the Covid Booster shot.
These two things will not mean you won't get COVID, but if you do it won't be a serious illness, so you won't be hospitalized or die.

Avoid large crowds of people whom you don't know if they are vaccinated.

Wash your hands every time you come in after being out: grocery store, pharmacy etc.
If you are sick, do a home test for COVID.

If it's positive, call your doctor or a pharmacy to get free PAXLOVID, a drug that can shorten how long you are sick and test positive.

Isolate yourself from others to avoid spreading it until you test negative.

REPORT FROM THE FIELD BY RANDY CURTIS, M.B.A.

The European Association for Hemophilia and Allied Disorders (EAHAD)

The European Association for Hemophilia and Allied Disorders (EAHAD) was held in Manchester, UK in February this year. It is the scientific meeting for health care professionals, with the European Hemophilia Consortium being the other meeting held for Community Organizations (like NHF or HFA).

Attending EAHAD was like being at the United Nations. I heard both kinds of English, French, German and lots of Dutch being spoken. There were also delegates from Eastern Europe in very striking garments. Posters were presented from around the world, including the U.S., Africa and Australia.

Although the focus was on Europe, the science being presented had global implications. Treating patients with mimetics (e.g., Hemlibra) in Denmark or Côte d'Ivoire had the same laboratory results, but the patient reported outcomes were very different.

Gene therapy was a hot topic. The results of phase II and III trials for any number of gene therapy products were presented. Some did not exclude inhibitor patients, who received good results. There were also some "rebalancing" drugs that keep clots from dissolving instead of factor replacement. These drugs seem to work equally well in hemophilia A or B and are a potential solution for those with hemophilia B and an inhibitor.

Hemlibra is in use in much of Europe, but there are a number of Lower-Middle-Income-Countries that do not have access, yet. There was at least one country in sub-Saharan Africa that had adopted Hemlibra through a purchasing agreement with Roche (parent company of Genentech).

Dr. Glenn Pierce reported that 17% of the people with hemophilia in the world use 90% of the clotting factor. There has been no progress in the last 100 years for 85% of the global hemophilia population. He also pointed out that gene therapy may be a possible solution for the developing world with time.

REPORT FROM THE FIELD BY RANDY CURTIS, M.B.A.

Global Hemophilia Advocacy Leadership (GHAL) Summit

I was able to attend the Global Hemophilia Advocacy Leadership (GHAL) Summit virtually this year. This event was co-sponsored by Bayer and BioMarin this year. In years past, I had attended this meeting in several locations in Europe. It has always had excellent speakers and provided a training ground for advocates from all over the globe.

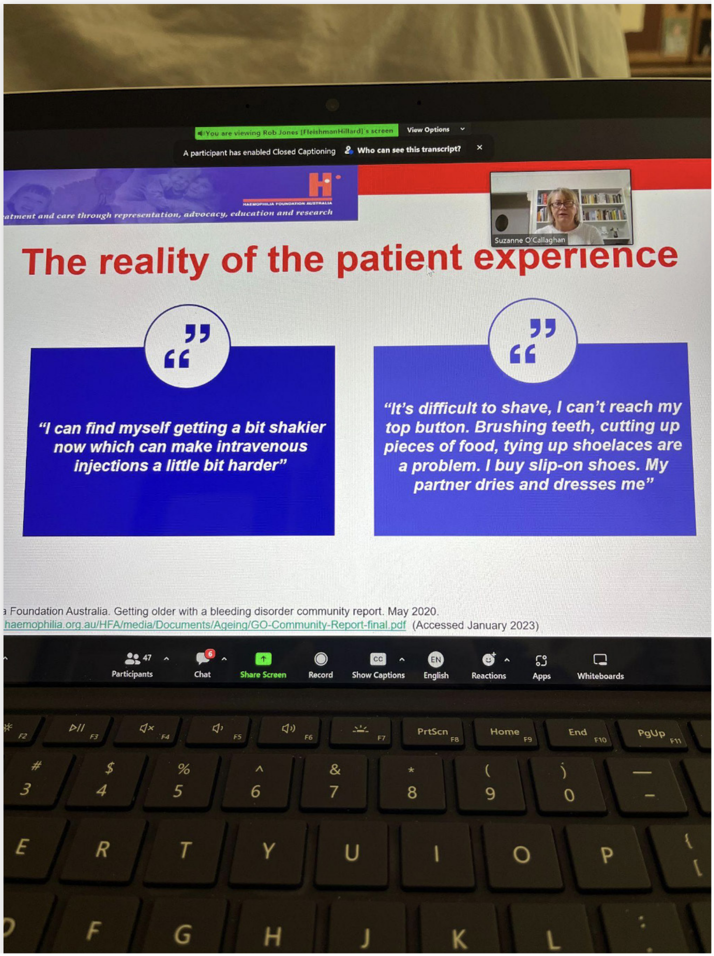
There were four case studies presented showing how to advocate for better care.

Poland had an existing hemophilia program that was functioning well until the bureaucracy decided it cost too much. They sent letters to the various legislators, a petition (with thousands of signatures) to the prime minister, and had reporters tell their story in the press as well as TV. They have secured funding until the end of 2023, and are gearing up for the next fight.

Australia uses the PROBE (Patient Reported Outcomes, Burdens & Experiences) tool to measure health related quality of life. They used this data to advocate for more support in their "growing older" population of hemophilia.

Nigeria started with one mother and her son in 1995 and partnered with the National Hemophilia Foundation (NHF) and the World Federation of Hemophilia (WFH) to build a network of 15 Hemophilia Treatment Centers (HTCs) and a registry of 730. They had to battle a belief the hemophilia was a white disease, or the result of witchcraft and continue to drop ship factor to those in war zones. One patient has not been able to get to the HTC for two years, because of the armed conflict, but he still gets factor.

The final story came from Pakistan, where a graduate from the Adult Fellowship for Integrating Responsible Mentors (AFFIRM) program established a 24 hour hotline to provide help to the four distinct regions of that country. Each of these regions speak a different language. This young man has recruited four men with hemophilia that are bi-lingual in one of these languages and volunteer to man the phones 24/7. They answer questions and can access doctors. They implemented this program while half of the country was under water.



A participant has enabled Closed Captioning

atment and care through representation, advocacy, education and research

The reality of the patient experience

"I can find myself getting a bit shakier now which can make intravenous injections a little bit harder"

"It's difficult to shave, I can't reach my top button. Brushing teeth, cutting up pieces of food, tying up shoelaces are a problem. I buy slip-on shoes. My partner dries and dresses me"

a Foundation Australia. Getting older with a bleeding disorder community report. May 2020.
haemophilia.org.au/HFA/media/Documents/Ageing/GO-Community-Report-final.pdf (Accessed January 2023)

I am proud to work with GHAL, PROBE and AFFIRM and see the amazing things that can happen in our community. It makes me all the more focused in improving what we can do in Northern California.

The Hemophilia Foundation of Northern California

FOR ALL BLEEDING DISORDERS

Family Camp Memories

2023

Taylor Family Foundation

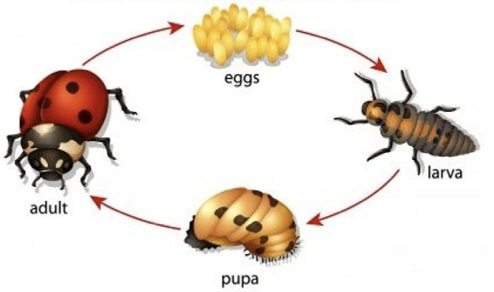
sanofi

Kid's Page

Happy Spring, Kids!

Have you ever wondered how a ladybug gets to be a ladybug? Even if you haven't, it sure is cool to see how special this garden friend is! Check this out!

Coccinellidae (ladybug) Life Cycle



SPRING

M	P	N	E	S	T	A	I	H	W	F	D
B	U	K	Q	A	P	N	D	R	A	I	N
I	Z	D	L	H	E	W	R	E	R	C	B
R	G	T	X	E	F	R	O	G	M	J	U
D	N	F	R	B	A	S	P	R	I	N	G
S	A	G	D	W	Y	F	J	H	B	O	S
T	E	L	K	O	B	U	D	S	M	P	C
N	V	E	S	R	H	G	I	X	A	B	W
Y	G	T	D	M	O	L	P	F	Y	E	I
S	R	V	A	S	J	K	I	T	E	C	N
A	O	M	E	L	T	H	B	R	S	W	D
C	W	U	P	I	D	F	T	M	Q	A	R

BUDS
BUGS
BIRDS
DROP
FROG
GREEN
GROW
KITE
LEAF
MAY
MELT
MUD
NEST
RAIN
SEEDS
SPRING
TREE
WARM
WIND
WORM

Lady Bug Fun Facts:

1. Ladybugs can eat up to 5,000 aphids in their lifetime. (Aphids eat vegetables in your garden and can destroy crops!) This makes ladybugs a farmers best friend!

2. Ladybugs aren't always red. (They can even be yellow or have stripes!)

3. Ladybugs hibernate.

4. Ladybug spots (or stripes) are a warning to birds. They say "don't eat me, I am toxic!"

5. Guess what else? Ladybugs can emit stinky blood from their joints to keep predators from eating them!

6. When all else fails, ladybugs can play dead to stop predators from eating them.

Spring Riddles:

1. Q: Does spring March?

2. Q: Which month is the shortest?

3.Q: When is the best time to wash a slinky?

4.Q: When is it impossible to plant spring flower bulbs?

5Q: What did the seed call the flower?

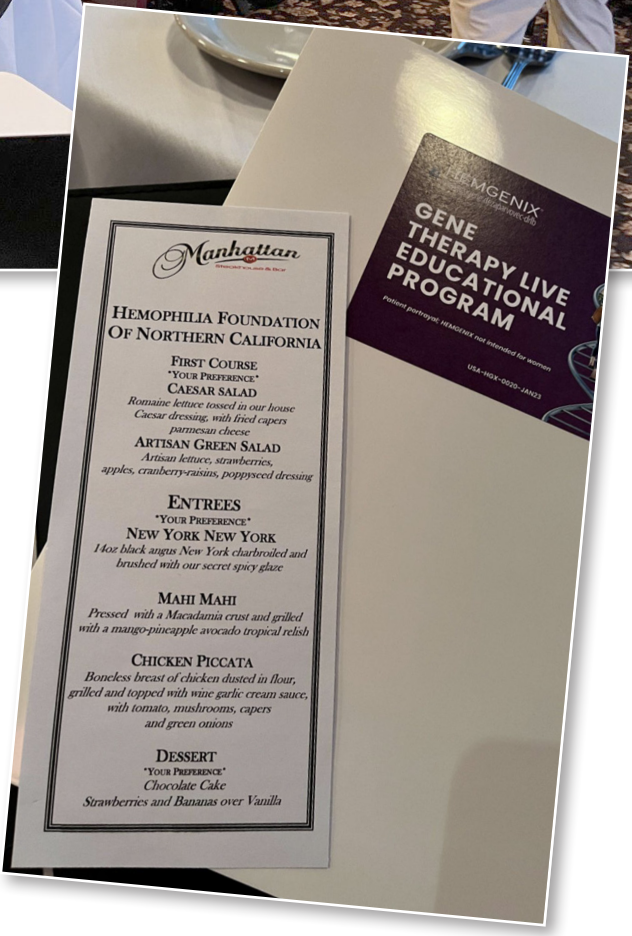
6.Q:I fall, but I don't get hurt. I pour, but I'm not a jug. I help plants grow, but I'm not the sun. What am I?

1.A: No, but April May! 2. A: May, it only has three letters! 3.A: When you are doing spring cleaning!
4. A: When you haven't botany (a botanist works with plants)! 5.A: A baby bloomer. 6.A: Rain.

REPORT FROM THE FIELD BY RANDY CURTIS, M.B.A.

Fresno Education Dinner

CSL Behring hosted an educational dinner in Fresno on February 23. Twenty seven people heard Dr. Doris Quon present the latest on Etranacogene dezaparvovec (HEMOGENIX) the first gene therapy product to be licensed for hemophilia in the USA. HEMGENIX is for people with factor IX deficiency (Hemophilia B). Clinical trials of severe and moderately severe patients resulted in an 54% reduction in annual bleed rates (ABR) with 94% of the participants no longer needing prophylaxis with clotting factor. Members of the Fresno Unified school district were there as well to find out more about care for the four children with hemophilia in their district.



Manhattan
Steakhouse & Bar

HEMOPHILIA FOUNDATION
OF NORTHERN CALIFORNIA

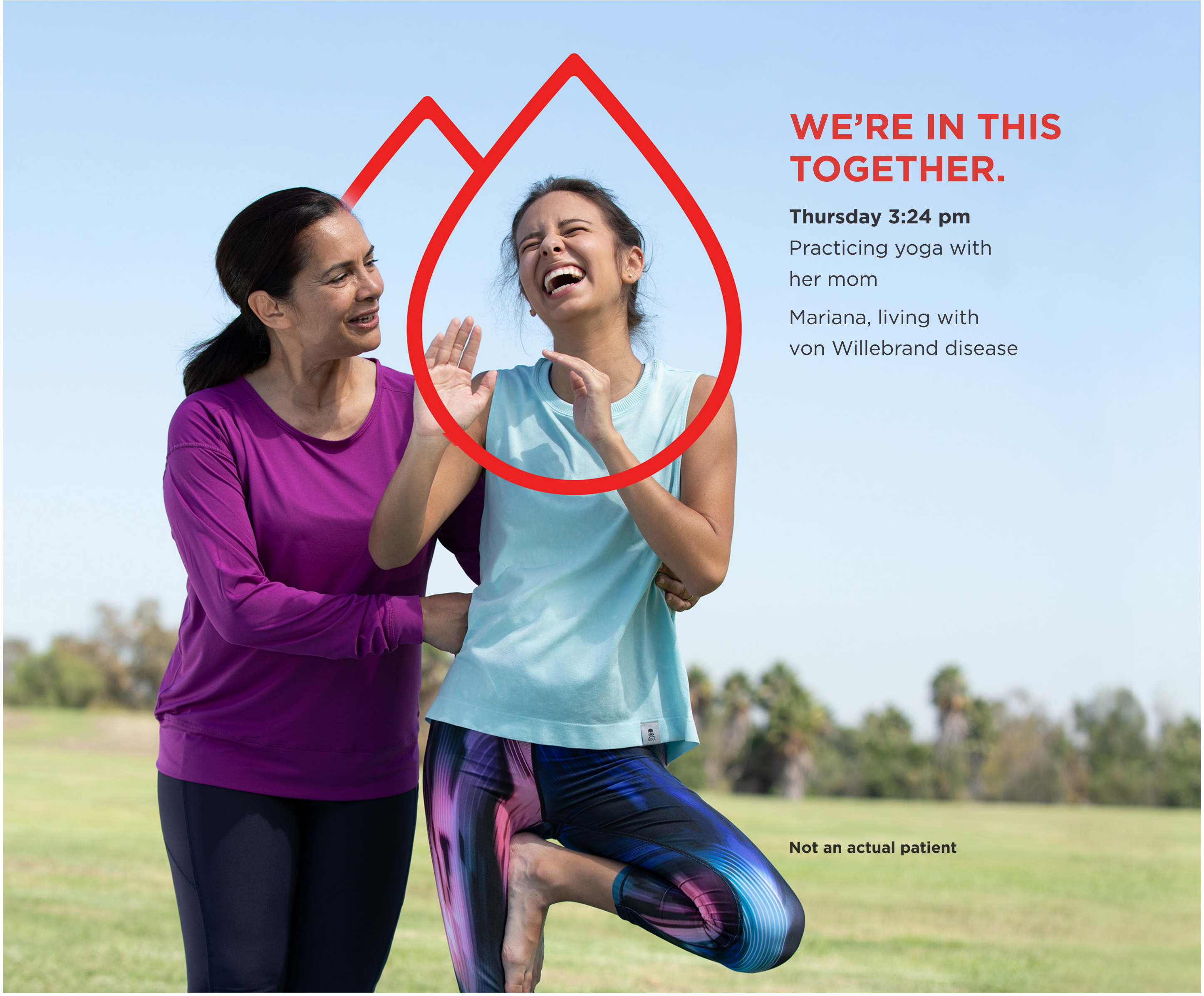
FIRST COURSE
"YOUR PREFERENCE"
CAESAR SALAD
Romaine lettuce tossed in our house
Caesar dressing, with fried capers
parmesan cheese
ARTISAN GREEN SALAD
Artisan lettuce, strawberries,
apples, cranberry-raisins, poppyseed dressing

ENTREES
"YOUR PREFERENCE"
NEW YORK NEW YORK
14oz black angus New York charbroiled and
brushed with our secret spicy glaze

MAHI MAHI
Pressed with a Macadamia crust and grilled
with a mango-pineapple avocado tropical relish

CHICKEN PICCATA
Boneless breast of chicken dusted in flour,
grilled and topped with wine garlic cream sauce,
with tomato, mushrooms, capers
and green onions

DESSERT
"YOUR PREFERENCE"
Chocolate Cake
Strawberries and Bananas over Vanilla


WE'RE IN THIS TOGETHER.
Thursday 3:24 pm
Practicing yoga with her mom
Mariana, living with von Willebrand disease
Not an actual patient

JGP POSTDOCTORAL RESEARCH FELLOWSHIP

Established in 1972

What is JGP?

NHF's premier research fellowship program is named in honor of Dr. Judith Graham Pool. Dr. Pool's work changed the landscape of care for people living with hemophilia. The fellowship funds early researchers to inpire a career supporting the bleeding disorders community. JGP-funded projects have contributed to the development of safer concentrates, enhanced methods of testing and screening, and have laid the groundwork for current advances in gene therapy for hemophilia.

Why support?

"Research creates discovery, discovery creates change, and change creates impact for people with inherited bleeding disorders"
- Len Valentino, MD, NHF CEO & President

"The JGP grant was indeed pivotal in my early career both for funding and for a feeling of connection to the NHF and hemophilia community afterwards."
- Gordon Vehar, VP External Innovation, BioMarin Pharmaceutical Inc. JGP Fellow

How much is funded?

NHF has funded over $9 million in fellowships, which has been awarded to 106 researchers. Each fellow receives $52,000/year for a 2-year grant cycle. The JGP Research Fellowships are made possible by the generosity of our chapters, individual donors, and foundations.

Selection Process:

- Applicants submit an extensive outline of their project proposal.
- Applications are reviewed in a peer review process by confidential, well-established scientists in the field volunteering their time at NHF.
- The process is the same as the National Institute of Health - reviewing Significance, Approach, Innovation, Investigator, and Environment.
- If selected, funding is distributed after contracting is complete. NHF Research Department and Finance Department monitors and audits progress every six months.

NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

Pathway to Cures

NATIONAL HEMOPHILIA FOUNDATION

Pathway to Cures is the National Hemophilia Foundation's venture philanthropy fund – a venture fund which invests in early-stage science-based companies researching and developing cures, therapies, and enabling technologies to address unmet needs in the inheritable blood and bleeding disorders community.

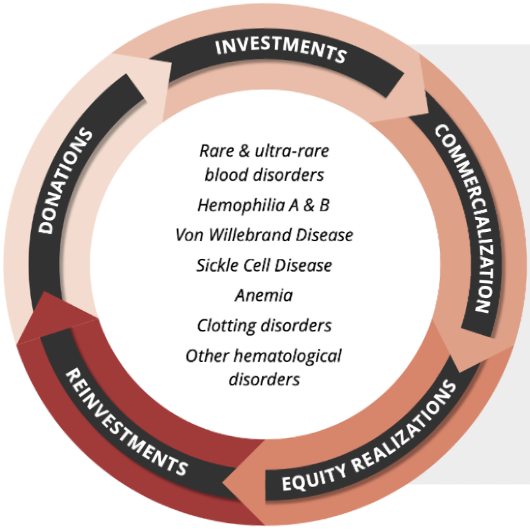
Pathway to Cures is referred to as a *venture philanthropy* fund because we invest like other *venture* funds receiving equity in the companies we invest in. The source of our funds for investment are *philanthropic donations.* Realizations (revenue received for the value of the equity we have acquired through investing) are returned to Pathway to Cures for further support of the National Hemophilia Foundation's mission including continued investment in companies advancing cures and therapies.

Pathway to Cures is one of the ways the National Hemophilia Foundation works to deliver on the mission of bringing cures to the community.

Pathway to Cures has:

- $5.5 million to invest in companies and carry out operations including raising additional money through donations. The goal is to raise at least $20 million and we are seeking pledges of a minimum of $500k.
- 2+ FTE's dedicated to Pathway to Cures which includes Teri Willey, Managing Director (November 2022), Renee Peck, Senior Development Director (December 2022), Tim Brent, Senior Director Business Development for NHF and P2C.
- The support of NHF's senior leaders with Len Valentino, CEO for Pathway to Cures (NHF President and CEO), Peter Harvey CFO for Pathway to Cures (NHF CBO) as well as the support of Dr. Michael Recht, NHF CMO & CSO; Dawn Rotellini, NHF COO and Brett Spitale, NHF Senior Vice President for Advancement.
- A Board of Directors chaired by Scott Martin (also the Chair of the NHF Board of Directors).
- An Investment Committee chaired by Brian Andrew (a former Chair of the NHF Board of Directors) and which includes three other experienced investors;
- A Scientific Advisory Group chaired by Dr. Michael Recht, our new CMO & CSO at the NHF;
- Actively considering investments, meeting with potential co-investors and fund raising.
- Website with more details: www.pathwaytocures.org

If you would like to learn more, have a discussion, have me present to your chapter, recommend a company for investment or introduce a potential donor, please don't hesitate to contact me: Teri Willey, Managing Director, NHF's Pathway to Cures Venture Philanthropy Fund, twilley@pathwaytocures.org



Donations made to Pathway to Cures are invested in early-stage companies developing therapeutics, diagnostics, and devices to address unmet medical needs.

These investments support commercialization of products for the bleeding and blood disorders community, which benefit the community, and provide returns to Pathway to Cures in the form of equity realizations. These realizations are reinvested amplifying impact and creating a sustainable funding program to support our mission for the bleeding and blood disorders community.

Life as a Female Hemophiliac by Pamela Lauer

Call Me Spontaneous

Dear Reader, my name is Pamela. My father was a hemophiliac, so am I. However, until I was 38, I was always called a "carrier" for hemophilia A. In 2014 I had surgery and when almost a month later I still hadn't clotted...that's when I was diagnosed a "carrier with symptoms". Today, after three knee surgeries and a lot of support from my HTC in Portland and San Francisco, I am finally labeled a "mild hemophiliac". Many would call this progression a huge step forward. It is a win for women with hemophilia just to be titled hemophiliac in their medical files. Female hemophiliacs are less common than males, and it's been a long road even admitting to myself that I am a bleeder. Even mild hemophiliac isn't an accurate description of me. In fact, most mild bleeders I meet tell me they are anything but mild.

Mild...what does mild mean? According to the American Heritage College Dictionary: "Gentle or kind disposition, moderate in type, degree or effect, not extreme." *Gentle? Not extreme?* Five hours on an emergency room table bleeding, three sets of sheets I bled through before they even decided to ask me if I had a history of bleeding in my family. Mild? I infuse, on average, two times a week...just to be able work in my garden or walk my dogs. Average number of stabs before a vein placement? 4. Sometimes it's as much as 9 times. That is *NOT MILD.* There is nothing "gentle" about hemophilia. My life is pretty extreme.

More importantly, "mild" hemophilia actually means, inconsistent. Spontaneous, if you will. There are weeks when I can accomplish all my tasks with no issues. Then, a week later, I can be doing the same chore I did last week, and boom! A bleed. For me, that means asking my husband to help me place a vein, if he's home. Or driving to the local emergency room for their help. They use a vein finder to find my veins.

After finding myself unable to work, and unable to place my own vein, I have been given a chance to try Hemlibra. Mostly due to my inability, or the inability of most nurses, to place a vein. A little bit due to the rural life I live. I have just begun taking this product. I was nervous it wouldn't help; I am nervous that the side effects will outweigh the benefits. So far, a month and a half in, I have yet to experience one bleed. I wonder if the emergency room nurses miss me!

My point is...I am okay with change, I am willing to try new things, especially if they help! But I am not okay with misnomers. If there is one goal I have for my health that is not a personal goal, it's to help change that word. No one is a mild hemophiliac. Bleeding for no reason, it's not mild! If a person bursts into flames for no reason, they spontaneously combusted. According to that same American College dictionary, spontaneous is described as: "Happening or arising without apparent external cause; self-generated." Sounds great so far...what else? The third definition of spontaneous states: "Unconstrained and *unstudied* in manner or behavior." Unconstrained? Unstudied? Boom. Mic drop. I prefer to be called a spontaneous hemophiliac. What is your preferred bleeding disorder diagnosis title?

Spontaneously Yours, Pamela

The Hemophilia Foundation of Northern California

FOR ALL BLEEDING DISORDERS

BAYER

THE FEMALE FACTOR
affected and connected

octapharma®

Takeda

The Hemophilia Foundation of Northern California

FOR ALL BLEEDING DISORDERS

PaintTheTown.Events

Paint Party - February 17, 2023

BAYER

THE FEMALE FACTOR
affected and connected

octapharma®

Takeda

The Hemophilia Foundation of Northern California
FOR ALL BLEEDING DISORDERS

THE FEMALE FACTOR
affected and connected

The Female Factor Retreat 2023

JOB READINESS GRANT

The Job Readiness Grant provides up to $1,000 for a skills course, certification, or training.

The grant can also cover materials needed to access the course such as a computer, specialized uniform, or supplies.

Applications are processed as soon as they are received with payments and materials provided within one month of applying.

CONTACT US

If you have questions or need assistance, please contact the Helping Hands staff at:

✉ helpinghands@hemophiliafed.org
☎ 202-675-6984

USE THE QR CODE TO APPLY!

Hemophilia Federation of America™

JOB READINESS GRANT

EXAMPLE TRAININGS:

- Phlebotomy technician certification
- Customer service
- Dog groomer
- Medical billing and coding
- Salesforce administrator
- Veterinary assistant
- Marketing and event planning
- Fitness and nutrition coach
- Peer support specialist
- Foreign language
- Project management
- SQL certification
- Course plus subscription
- Electrician apprenticeship
- And many many more!

ELIGIBILITY

- Have a diagnosed bleeding disorder or are a carrier
- An adult between 18 to 64 years old
- Seeking assistance for a skills course, certification, or training program
  **college courses considered*
- Not a past receipient of a Job Readiness Grant, an HFA board member, an HFA staff member, or the immediate family members of HFA board or staff members.

APPLICATION

✓ Complete the brief online application

✓ Provide a brief statement about the barriers to employment you have faced and how the specific course, certification, or program will help you gain or keep sustainable employment

✓ Proof of a bleeding disorder

✓ Your resume

✓ Documentation of the course, certification, or program cost

✓ A reference letter (optional)

The Hemophilia Foundation of Northern California

FOR ALL BLEEDING DISORDERS

YOU'RE INVITED!

Walk
10/1
8AM Registration
9AM Start
at
Heather Farm Park
301 North San Carlos Drive
Walnut Creek CA 94598

START YOUR TEAM!

Register hemofoundation.org/events

Unite for Bleeding Disorders

CALENDAR

MAY

4/3/23-4/4/23	NHF Regional Walk Meeting	BioMarin, San Rafael CA
5/7/2023	SpringFest/Walk Launch	Fresno City College, Fresno, CA
5/9/2023	Board Meeting	Virtual
5/29/2023	Memorial Day	Holiday HFNC closed

JUN

6/13/23	Board Meeting	Virtual
6/25/23-7/1/2023	Camp Hemotion	Camp Oakhurst, Coarsegold CA

JULY

7/4/23	Independence Day	Holiday HFNC closed
7/11/23	Board Meeting	Virtual
7/23/23	Community Celebration of Val Bias	AIDS Grove, GG Park, SF
TBD	Disabled Adventure Outfitters	TBD
7/24/23-7/28/23	Strategic Planning/HFNC closed	In person*

AUGUST

8/8/23	Board Meeting	Virtual
8/17/23-8/19/23	Bleeding Disorders Conference NHF	Washington DC

SEPTEMBER

9/4/23	Labor Day	Holiday HFNC closed
9/8/23-9/10/23	Familia de Sangre	Anaheim
9/12/23	Board Meeting	Virtual

OCTOBER

10/1/23	Walk	Heather Farm Park Walnut Creek CA
10/10/23	Board Meeting	Virtual
10/23/23	Golf	Ruby Hill Golf Club Pleasanton CA

NOVEMBER

11/4/23	Emerging Therapies	OakStop, Oakland CA
11/14/23	Board Meeting	Virtual
TBD	NHF Chapter Leadership	TBD
11/23/23-11/24/23	Thanksgiving Holiday	Holiday HFNC closed
11/28/23	Giving Tuesday	Campaign

DECEMBER

12/1/23	World AIDS Day	AIDS Memorial Golden Gate Park San Francisco, CA
12/2/23	WinterFest	East Bay
12/9/23	WinterFest	Fresno
12/24/23	Christmas Eve	Holiday HFNC closed
12/25/23	Christmas Day	Holiday HFNC closed
12/24/23-12/31/23	HFNC Office Closed	Holiday HFNC closed

JANUARY 2024

1/1/24-1/2/24	New Year's Day	Holiday HFNC closed
1/3/24	HFNC reopens	Virtual

HFNC Hemophilia Foundation of Northern California
https://www.hemofoundation.org/

AFFILIATED ORGANIZATIONS

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

HFA Hemophilia Federation of America
http://www.hemophiliafed.org/

NHF National Hemophilia Foundation
https://www.hemophilia.org/
NHF Chapters (See full list at NHF):

WFH World Federation of Hemophilia
https://www.wfh.org/

HEMOPHILIA TREATMENT CENTERS HTC's

Stanford University Medical Center
https://www.stanfordchildrens.org/en/service/hematology

UCSF Benioff Children's Hospital Oakland
https://www.childrenshospitaloakland.org

University of California at Davis
https://www.ucdmc.ucdavis.edu/hemophilia/

University of California San Francisco
https://www.ucsfhealth.org/clinics/hemophiliatreatment_center/

Valley Children's Hospital
https://www.valleychildrens.org/

HOSDC
HEMOPHILIA ASSOCIATION OF SAN DIEGO COUNTY

Hemophilia Foundation of Southern California

Central California Hemophilia Foundation

The Hemophilia Foundation of Northern California
FOR ALL BLEEDING DISORDERS

FAMILIA de SANGRE CONFERENCIA 2023

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8-10 de septiembre
Anaheim Marriott

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Asian Infusion


Madonna McGuire Smith

Parents that adopt children from China with bleeding disorders got together to share about the experience at our World Hemophilia Day Event

Attendees were inspired to learn and even look in to adopting


Shari Luckey


Nancy Golden

Thank you to our sponsors & panelists for an enlightening and inspiring event!

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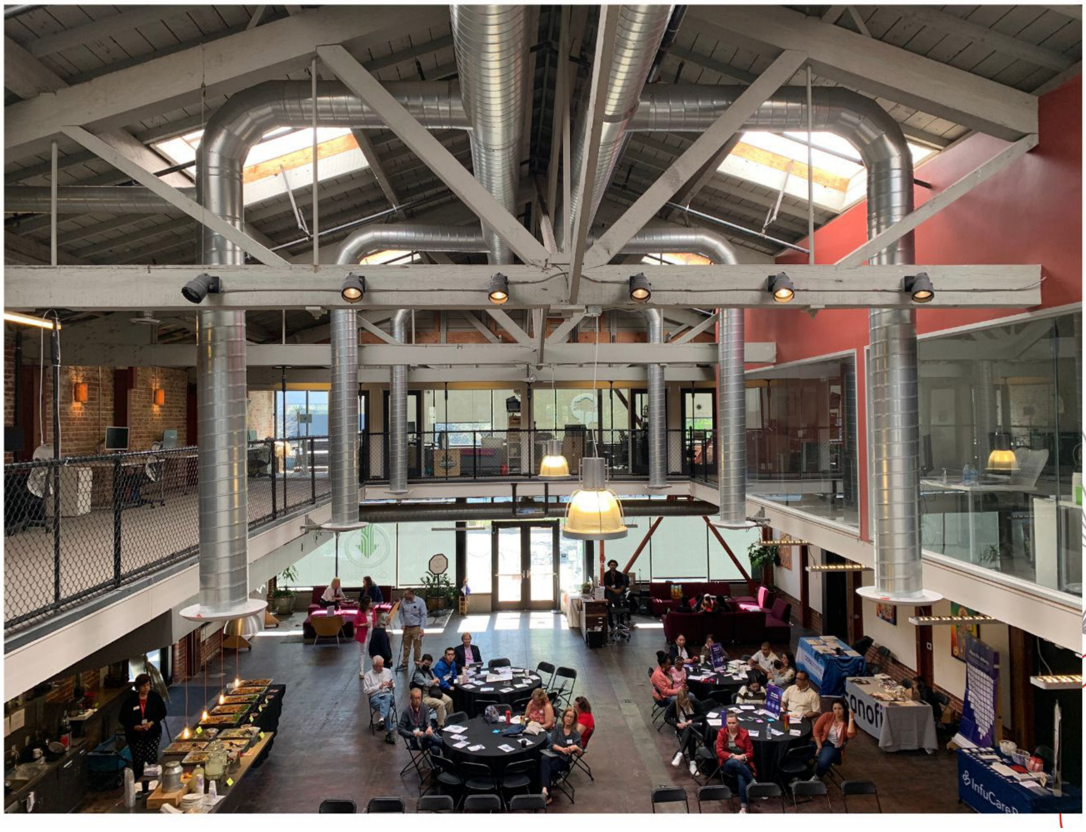
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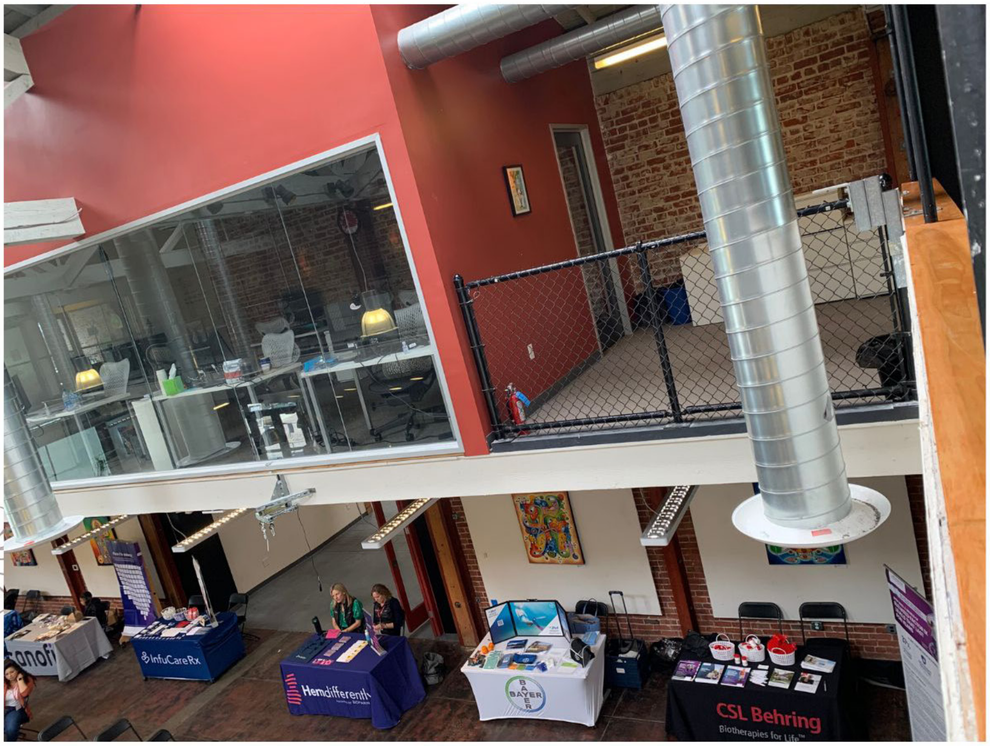


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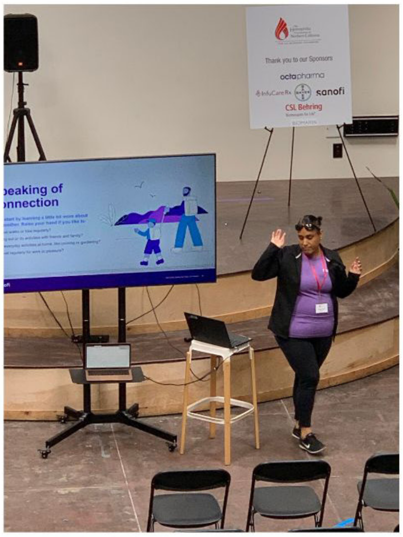

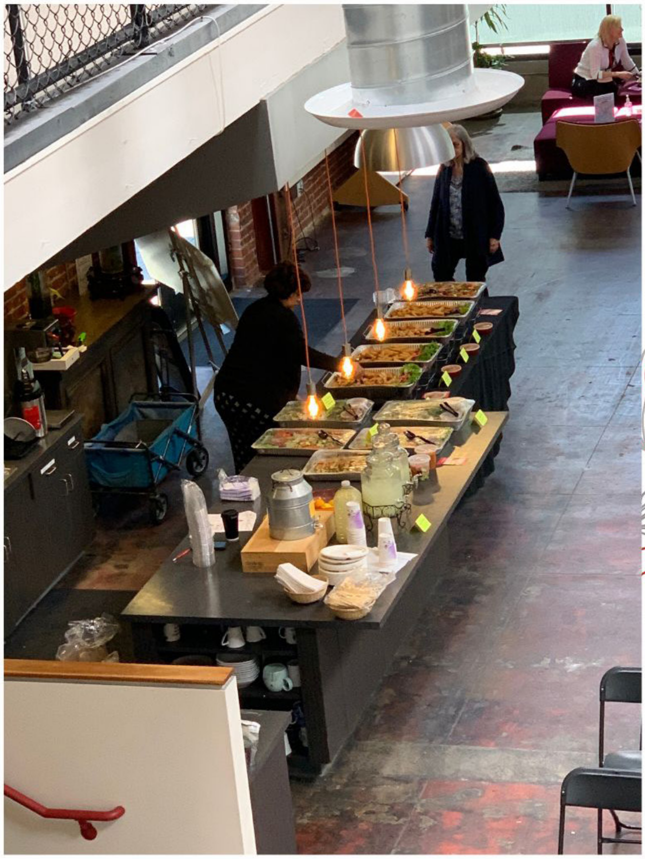

World Hemophilia Day & Asian Infusion Rolled into One Great Day

By Ashley Gregory 5/10/2023

World Hemophilia Day was celebrated on April 22 by HFNC this year by including Asian Infusion, our program that honors our Asian brothers and sisters in the bleeding disorders community of Northern California. Over a year and a half in the making by the Asian Infusion committee, HFNC was thrilled to be able to provide a panel of parents from across the United States. Adoptive parents Madonna McGuire Smith, Nancy Golden and Shari Luckey relived the heartwarming and tear jerking but often gut wrenching and harrowing details of how they were able to overcome odds to bring a child with bleeding disorders from China home to the United States and their family.

Attendees were inspired and intrigued as they got to know the children through the tales the parents told. One family that attended was inspired to look into the process and learn if it may be something in their future. HFNC hopes to support them in that journey. In addition to the compelling panel topic and discussion, the new venue in Oakland, OakStop was a surprise win. New to HFNC, it was incredibly well received by the attendees. OakStop provided comfort as well as modern aesthetics and easy access to outdoors. The food spread was raved about and the seconds and thirds line was a testament to the delicious array of thai cuisine. The child activity area was managed by Nicholas DeFalco, Camp Hemotion adult counselor. The children truly enjoyed the thoughtful activities and ability to play in the open area. This was also an opportunity for our community to participate in two world inspired activities; Sanofi provided bracelets and cards for attendees to create and send to those in need of care for their bleeding disorders in developing countries via Save One Life organization and HFNC hosted a *Where in the World are You From?* activity complete with wall size world map and sticky notes for attendees to affix to the map indicating where their ancestors or they hail from. We were intrigued to see the variety of ethnicities we come from in our community. Finally, there was a lucky red envelope activity with one big winner that was a fun way to wrap up our world events and transition to our panel about adopting children from China. Event sponsor booths provided valuable information and resources and were visited by all and two very lucky passports were pulled for fun prizes at the end of the day.

Lastly, HFNC had a first of our own as we introduced Pedro Preciado , HFNC's bilingual Community Outreach Coordinator to the community at their first event in their new role. We all welcomed Pedro and hope you will join us in the future. We hope to continue this tradition of bringing the world together at our events for World Hemophilia Day and Asian Infusion. We welcome your ideas for future World Hemophilia Day celebrations and encourage you to contact us with your ideas.

Email ashley.gregory@hemofoundation.org
510-658-3324 (call/text)

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July 23, 2023

2-4PM

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CONTACT INFORMATION

Hemophilia Foundation of Northern California
1155-C Arnold Drive #236
Martinez CA 94553

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

www.hemofoundation.org

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Editor
Ashley Gregory, *Education & Advocacy Director, HFNC*

Medical Editor
Marion Koerper, M.D.

Contributors
Shelley Jajeh & Pamela Lauer

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