



Hawaii Chapter

NATIONAL BLEEDING DISORDERS FOUNDATION

E-NEWSLETTER
ISSUE IV



2024

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In Loving Memory of Dr. Marion Koerper



On Wednesday, December 18th, we lost Dr. Marion Koerper UCSF Hemophilia Treatment Center. Her years of involvement with the bleeding disorders has made a huge impact and helped provide many opportunities for community members. Please see the official announcement regarding her passing below, written by Randy Curtis, President of Hemophilia Foundation of Northern California.

Her Dedication and Compassion Will Forever Inspire Us

Dr. Marion Koerper passed away early Wednesday morning, December 18, 2024, after a courageous battle with glioblastoma. A dedicated physician and educator, Dr. Koerper completed her undergraduate studies at Stanford University and earned her medical degree from the University of California, San Francisco (UCSF), where she met her future husband Dr. Bob Blumberg. She was a professor emerita (she would be pleased that I got the Latin correct) of pediatric hematology at the University of California, San Francisco (UCSF) and the founder of the UCSF Hemophilia Treatment Center.

Dr. Koerper was drawn to hematology and developed a profound interest in hemophilia. She worked alongside Dr. Shelby Dietrich, who pioneered the use of team-based meetings to provide comprehensive care at hemophilia clinics. Throughout her career, Dr. Koerper collaborated closely with the National Hemophilia Foundation and the World Federation of Hemophilia on global initiatives to improve care for people with bleeding disorders. Dr. Koerper was involved in many research projects and was widely published:

<https://profiles.ucsf.edu/marion.koerper>. She was a passionate advocate for her patients and a leader in advancing treatment options worldwide.

Dr. Koerper served as a medical advisor, president, and board member for the Hemophilia Foundation of Northern California (HFNC). Dr. Koerper and Susan Karp, RN created a summer camp for children with hemophilia in 1978, which eventually became Camp Hemotion. For over 30 years, she staffed the camp's infirmary, ensuring that campers received exceptional care and enjoyed a safe and enriching experience. Her dedication extended beyond medicine to mentorship; her wisdom and compassion left an indelible mark on countless lives. If I had a child in my cabin that didn't want to swim, I'd send him down to the infirmary, saying "If Dr. K says you can't swim, you don't have to swim. Otherwise, you're going into the pool".

In Loving Memory of Dr. Marion Koerper

Dr. Koerper played a pivotal role during the AIDS epidemic, which devastated the hemophilia community in the 1980s. Her resilience and leadership were unwavering as she guided patients, families, and colleagues through one of the darkest chapters in medical history. The epidemic's toll on her patients was deeply personal, yet she continued to fight for better treatments and support systems, even stepping in to lead the HFNC during this challenging time.

Dr. Koerper's contributions to the field were recognized on a national and international scale. She received the Lifetime Achievement Award from the National Hemophilia Foundation and was revered wherever she went. Her legacy is one of compassion, innovation, and dedication to improving the lives of those with bleeding disorders.

Services for Dr. Marion Koerper was held on Friday, December 20, 2024, at 1:00 PM in the chapel at Home of Peace Cemetery, 1299 El Camino Real, Colma, California. She is survived by her husband, Dr. Bob Blumberg, their two sons, and two grandsons. As we remember Dr. Koerper's monumental contributions to the hemophilia community, let us celebrate her extraordinary life and enduring legacy.

Forever grateful for her friendship, Randy Curtis

Donations in Dr. Koerper's memory can be made to the HFNC Camp Hemotion Scholarship Fund at the link below.

DONATE TO CAMP SCHOLARSHIPS

2024 Unite Walk Wrap Up



This year, we were one of 37 national walks that took place around the country, totaling over 5,697 participants and \$1.9 million raised.

For our personal walk this year, we finished with 16 teams and 70 registered participants bringing in \$13,820. We had a great turnout with our actual in-person event with entertainment by Andrew Aragon, games, activities, and snacks.

We had a great opportunity to work with Hiki No Tent Rental, a local family business, who gave us a great rate on our tent rentals for 2024 Unite Walk. What used to cost us over \$3,000, we got from Hiki No for just over \$1,000. Unfortunately, their family is moving to the mainland and will no longer be continuing their business so if anyone has any tent rental companies you'd like to suggest, please reach out!

Tahoe Pieklo led us through our Pinwheel Ceremony before we took our lap around Kapi`olani Park. After that, participants had the opportunity to look around at our sponsors booths, as well as get their face painted by artists from Storybook Entertainment.

We also had a remote walk on Maui, organized by the Hu`eu Ohana and sponsored in part by Octapharma. During the day of their walk celebration, they were able to bring in over \$1000 just from family and friends attending their event!!

We had 4 factor club winners during the time of our walk, but we have been doing so great with continued fundraising that we had someone else since join our Factor Club Group! Those who fundraised a certain amount had a choice between two different prizes this year instead of having a set prize. I thought that made it a lot more interesting and exciting to have the power to make that type on decision.

2024 Unite Walk Wrap Up

Our top team captain was Ashley Pieklo and for our incentive competition with two tickets to Body Glove Adventure Tours was Jen Chun! We also got recognized as a Rising Star Chapter- we had more than 45% participant activation and an increase in fundraising team captains by 5%!

Thank you again to our National and Local sponsors:

- National Presenting Partners: Takeda and Hemophilia Alliance
- National Community Partner: Sanofi
- Virtual Partners: Genentech and Spark Therapeutics
- Local Sponsors: CSL at Gold, Accredo and Octapharma at Bronze
- Remote Sponsor: Novo Nordisk

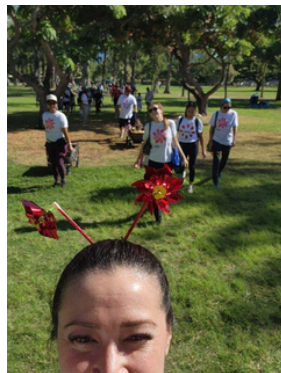
2025 Unite Walk Launch Party

We will have a 2025 Unite Walk Launch Party on January 29th at 10AM HST. We highly recommended you listen in, especially if you are a team captain!

[REGISTER TO ATTEND THE LAUNCH PARTY](#)

2025's Unite Walk page is now active! We have a goal of \$30,000 and am working on bringing Facebook fundraisers back so that your walk page will be connected to a Facebook fundraiser.

[CHECK OUT THE 2025 WALK PAGE](#)



6th Annual Golf Tournament Fundraiser



This past Golf Tournament was a huge success. We held our tournament at the beautiful Hokuli`a golf course in Kona on November 11th. We had just about 90 participants registered to golf and another 7 volunteers!

We had a shotgun start at 10am and had beverage carts and coolers along the course filled with refreshments. While the golfers were out, my amazing team of volunteers helped tear down registration tent and move all our donated silent auction gifts and refreshments to the banquet space.

Silent auction items lined the outer perimeter of the meeting space so that once the golfers came back, they were able to roam around and place their bids! We had some big prize items like rounds of golf at Hokuli`a, Pearl at Kalauao, a custom made ukulele, and items from local small businesses like Coco Moon and Kaleimamo!

We had amazing live entertainment from local entertainer Haunani Wehrsigg during lunch. You can find her on Instagram under @haunanimusic to see her performance schedule. The meal was catered through KBXtreme and sponsored by Knutson & Associates. Prizes were then given out to all of our winners. We had 6th place as the grand prize winner to commemorate our 6th annual golf tournament, followed by 1st and 2nd place.

6th Place

Brett Komatsu and Jaryn Kanbara

1st Place

James Ribara and Cody Coman



2nd Place

Brock Kuntz and Darrel Fetzer

Men's Longest Drive

Jaryn Kanbara

Men's Closest to the Pin

Ikaika Ogawa

Women's Longest Drive

Nancy Kamaka

Women's Closest to the Pin

Nancy Kamaka

Thank you again to our Sponsors:

- The Office of Garrett Ota, DSS



CSL Behring

octapharma®



KNUTSON & ASSOCIATES



Mahalo to all who donated:

- Jim Skibby
- Haunani Wehrsig
- University of Hawaii Baseball
- University of Hawaii Men's Volleyball
- Ola Tropical Apothecary
- The Most Irresistible Shop in Hilo
- Coco Moon
- Pepsi Kona
- Mike Duty
- Waiakea Water
- Odom Corp
- Pearl at Kalauao
- Kona Brew
- Maui Brew
- Lehua Creations
- Jae Shimabukuro
- Makau Nui
- Capoeira Besouro Hawaii
- Body Glove
- Ka Alala
- Sabra Testa
- Russell Mitsuda
- Makalei Golf Course
- Hamakua Creations
- Kat's Creative Kreation
- Tin KR Designs
- Korey's Kreation
- Charlene Matsuoka
- Kaulukaika
- Moai Hawaii
- Hualalai Golf Club
- Komo Estate Coffee
- Hokuli`a Golf Club
- Kaleimamo Hawaii
- Mauna Lani Golf Course
- kona Country Club
- HI Score- Kona Pinball

December Voices

We had a great attendance at December Voices this year from both the community and National Staff! We had 39 community members, 6 HTC staff, 4 staffers from National, 11 sponsors, and 5 outer company staff members. We got the opportunity to do breakout rooms for the men and women and discuss fundraising, mental health, and more.

We had a great opportunity to meet Santa at Saturday's dinner where he passed out toys to all the kids! The kids had a great time dressing up in holiday pajamas and playing games with each other. Many great topics were presented including the History of NBDF, a Racial Wealth Gap simulation, and Thrive launch party! We also did a generation gap game that the kids loved! They would not get enough! The kids won fair and square, leaving the adults out to dry. If you missed December Voices, there is always this year!

Mahalo to our sponsors:

Platinum: 

Diamond: 

Gold: 

Silver: 















Pie Fundraiser

Our Holy's Bakery Pie Fundraiser was a huge success! We bought 24 cases of pies (240 pies total) and sold out of them all before we even received them! In the past, we would have a few extras and slowly sell the remainder in the following weeks but these sold quick!

We had pies sold around Hawaii island, Maui, and O`ahu! We got a great deal on shipping to outer islands from a family friend, Uncle Garrick. What would have been over \$400 in shipping to outer islands was brought down to just over \$100! Shoutout to Uncle Garrick! At the end of it, we still came out with just over \$3,500 profit!

We were also blessed enough to get 15 pies sponsored by outer island families and co-workers who work for NBDF on the national level. These pies were then donated to the local Kona Fire Station, Catholic Charities Hawaii (Kona), and Hope Services Hawaii (Kona). Thank you to all who supported this fundraiser and can't wait to do it again next fall!

Upcoming Events

Jan 19	Board Meeting 3-5pm
Jan 23	Hilo HTC Outreach
Feb 8-9	Volleyball Tournament
Feb 10-11	State Advocacy Day (Prep and Visit)
Feb 27-28 (Tentative)	Maui HTC Outreach*
Feb 20	Couples Virtual Ed Session with Takeda
Feb 20-23	Yeti
Mar 5-7	WA Days
Apr 12-13	Ohana Education Weekend

WE'RE IN THIS TOGETHER.

Thursday 3:24 pm

Practicing yoga with her mom

Mariana, living with von Willebrand disease

Not an actual patient

Let's make today brilliant.

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to adult patients with von Willebrand disease is stronger than ever.

*Not all activities are appropriate for all individuals.
Consult your doctor prior to engaging in any activity.*

 bleedingdisorders.com | 

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State Hill Day (Honolulu)

Please consider joining us to go to our state capital and meet with our representatives to bring awareness to our organization and bleeding disorders as a whole! This will take place on Tuesday, February 11th. We are still working on meeting schedules with different offices but could use all the community support we can get! If you are interested in joining us for the day, please reach out to me (Kyra) as soon as possible. We will also be meeting for a training dinner (location tba) with our advocacy pro, Bill Robie, Monday, February 10th so that he can train us in certain issues we might be interested in bringing to their attention. You will have a great group of other advocates to lean on so please do not feel hesitant if this is your first time!

BDC Grant Link Out Now!

If you have ever wanted to attend the annual Bleeding Disorders Conference, now is your chance! They have opened up the application for travel grants to BDC for this upcoming year in Colorado! This multi-day event is packed with soo many sessions to choose from on more topics than you can even imagine! Please check out the BDC home page and take a look at the “Program at a Glance” section to see the different topics and breakouts planned, as well as the “Connections for Learning” section to see how you can apply for a travel grant!

[BDC Home Page](#)

[Program at a Glance](#)

[Connections for Learning](#)

Join NYLI Today!

NBDF's National Youth Leadership Institute 2025 Cohort application is now open!! If you are between the ages of 19 and 25 and interested in bettering yourself to be a young leader in our bleeding disorders community, please register! I myself have been through the program years ago and it has trained me on public speaking, advocating to powerful individuals, and being the best resource I can be to my fellow community members. I highly recommend this program to all of our young adults in our community!

Click here for more info!

National Youth Leadership Institute



NATIONAL BLEEDING DISORDERS FOUNDATION



Applications Close
March 1, 2025

Highlights

- Enhancing Leadership Skills
- Develop Professional Skills
- Networking + Opportunities
- 3 Tracks: Research, Education, and Advocacy

Requirements:

- Ages 19-24 years old
- Diagnosed with a bleeding disorder OR have a sibling with a bleeding disorder
- U.S Resident
- Able to travel to trainings and programs

For More Information:



Heather Hicks
hhicks@bleeding.org



Event Changes & Expectations

Some things have changed regarding event registration. After discussing with our December Voices attendees, we have decided to let O`ahu families opt out of staying in a hotel. You still have the option to stay if you would like, but if you are fine with staying at your house and driving over, we would offer you a gas card in return (amount will depend on mileage between house and venue).

We will also be asking on island families if they want to drive to/from meeting space (if it is different from hotel space) and we would cover that parking cost. This would help us cut down on purchasing larger transportation like a big tour bus. The price of meals through hotels are also skyrocketing so we are also looking at alternative food options like bentos vs buffets through the hotel.

As an attendee, we do expect you to be at the event for the whole duration of program. This includes participating in conversation, activities, and being a good role model to the kids to engage. There have been multiple times in the past where I have seen people try and sneak off to go shopping, take naps, etc during program time and that will no longer be tolerated. That may jeopardize your admission to future events. I love having you all together to learn and build relationships with each other, but please do not abuse some of the perks that come with it <3