



# Hawaii Chapter

NATIONAL BLEEDING DISORDERS FOUNDATION

E-NEWSLETTER  
ISSUE II



2025

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# Koko Ohana Family Camp

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From June 20-22, we held our annual Koko Ohana family camp at Camp Mokule`ia on O`ahu. We have used this campsite for years and they have always been easy to work with and accommodating of our group. This year, we had about 31 people attend, a little smaller than previous years, but we made the best of it, and it was nice to have a smaller, more intimate group.

From feedback we got at December Voices, we decided to give Koko Ohana a theme. This year's theme was Avatar, the Last Airbender. Participants got divided up into the four element groups and throughout the duration of camp, participants played mini games to gain points for their element group. These games included water balloon toss, basketball, cornhole, and much more! At the end of the weekend, it was FIRE NATION who pulled ahead with the win!

One other thing we changed this year from previous years was we reserved pool time instead of waterfront/beach time. From what it looked like, I think our community liked the pool time a lot better. People didn't have to battle against currents or waves, especially with the younger kids. Usually, people are done on beachfront time by the first hour mark, and I believe we had a couple of simmers in the pool the whole time this year.

At our infusion clinic this year, Cameron infused for the first time! He paced himself and made sure that he was completely ready and confident when making his moves. Bella also poked herself for the first time as well (no blood). Huge congratulations to both of them on their HUGE accomplishments! Cameron will be getting his Big Stick Award, and Bella will be getting a Stepping Stone Award.



## Mahalo to our Koko Ohana Sponsors

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Also, huge mahalo to Dr. Roger Yokoyama, DDS who donated and provided toothbrushes, toothpaste, and floss for our campers!

A camp grant from Colburn Keenan Foundation was also used to purchase beach and bath towels, wash cloths, shampoo, conditioner, body wash, and some other camp supplies so thank you Colburn Keenan Foundation!



# Annual Golf Tournament Registration Open

**Registration for the golf tournament is now live!** Our 7<sup>th</sup> Annual Golf Tournament Fundraiser will be a 2-person scramble and will take place on September 8<sup>th</sup> at Hokuli`a in Kailua Kona.

**Agenda will be as follows:**

8:30am: Registration and Warm Ups

9:45am: Announcements and Welcomes

10:00am: Shotgun Start (2-person scramble)

Lunch reception, prizes, and golf auction will follow

**We are also looking for donations! Donations will be split in 3 different categories:**

1. Items for golfer bags (snacks, discount cards, etc.)
2. Prizes for our tournament winners. Awards will go to first place (2), second place (2), and 7<sup>th</sup> place (2), which is the grand prize winners to commemorate our 7<sup>th</sup> anniversary.
3. Golf auction- Any golf related items will be up for bids during lunch reception. This can include gift certificates to different courses, gear, etc.

If anyone is able to contribute any sort of donations or needs an ask letter, please let me know and I would be more than happy to send one over!

If your company is looking to sponsor a team, please see the different corporate sponsor levels posted on the registration page, as well as attached below.

[Learn More & Register for the Golf Tournament](#)

Title Sponsor \$5,000.00	This sponsorship level includes two foursomes, an additional 8 guests to attend lunch/reception, logo on podium and event promo materials, 1 tee sign, 1 post on our social media accounts, a logo with clickable link to website of your choice in newsletter, and up to three individual items in golfer bags.
Eagle Sponsor \$2,500.00	This sponsorship level includes a foursome, an additional 4 guests to attend lunch/reception, logo on event promo materials, logo in following newsletter, and up to two individual items in golfer bags.
Foursome Only \$800.00	Includes admission for 4 golfers, as well as lunch and access to mini silent auction.
Twosome Only \$450.00	Includes admission for 2 golfers, as well as lunch and access to mini silent auction.
Single Golfer Only \$250.00	Includes admission for single golfer, as well as lunch and access to mini silent auction.
Tee Sponsor \$500.00	Only available as an add on option with any of the other sponsorship levels.



# Virtual Silent Auction

In efforts to open up our usual silent auction to a wider audience, we are moving it to an online platform. Golf specific items like golf course certificates will be for bid at the tournament, but all other donations that are not used for prizes will be moved to the online platform. The date for the online launch is October 1st and will close on October 31st. You can get a sneak peek of items for sale by following our social media accounts so make sure you are following them to stay updated. We are again looking for donations for this as well. In the past, we have had donations including certificates to activities around HI, artwork, jewelry, coolers, a ukulele, baby items, food, and assorted gift basket items. Please reach out if you or someone you know are willing to donate and I can send over an ask letter!

## Upcoming Events

August 6	Sanofi Branded Ed Dinner (Maui)
August 21-23	NBDF Bleeding Disorders Conference (Colorado)
August 25	Genentech Branded Ed Dinner (Maui)
September 8	Golf Hokulia (Big Island)
September 9	Novo Nordisk Ed Dinner "Pain Matters" @ Papa Kona (Big Island)
September 11	Novo Nordisk Ed Dinner (Maui)
September 12	Octapharma Ed Dinner (O`ahu)
September 13-14	Mana Wahine Women's Retreat
October 3	Genentech Ed Dinner (O`ahu)
November 13	HEMA Biologics Ed Dinner (Kauai)
December 5-7	December Voices
December 7	Unite Walk

[Register for Events](#)

# Event Expectations

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## Event Expectations for Attendees

To ensure the best experience for everyone and to help us continue offering valuable programs, we've outlined a few expectations for attendees. By registering for our events, you agree to these guidelines:

- **Commitment to Attend:** When you register for an event, we expect you to attend. Your registration helps us accurately plan for catering, materials, and venue capacity.
- **Cancellations:** If you're unable to attend an event you've registered for, please notify the chapter as soon as possible. This allows us to adjust our arrangements and potentially offer your spot to someone else.
- **Attendance Policy:** We understand that sometimes unforeseen circumstances can prevent attendance. However, if you frequently register for events and do not attend, it impacts our ability to provide events and services. The per-person cost for our events ranges from \$50 to \$1000, and we incur these costs whether you attend or not. Therefore, repeated no-shows may unfortunately result in you becoming ineligible to attend future events.
- **Support Our Sponsors:** Many of our events are made possible through the generous support of our sponsors. We encourage you to visit their booths and learn about their contributions. Your engagement with our sponsors helps us secure continued funding, ensuring we can keep offering these valuable events to the community.

We appreciate your understanding and cooperation in helping us make every event a success! If you have any questions, please don't hesitate to reach out.

## Share Your Voice

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### Call for Artwork

Any kids or teens want their artwork featured on the chapter website? Please send in artwork about Koko Ohana, the Unite Walk, or any other program and we will have it featured on our social media pages!

### Community Testimonies

We are looking for quotes or stories from community members to share in our newsletters and on social media! Please send in a quote or story on how the chapter has made a difference in your lives, your experience with attending certain events (can be used to promote program in the future), what being a part of the community means to you, etc! We would love to add some personal community voice to our social media pages.

## Unite Walk



Check out the great Walk prizes for 2025!

[Support the Walk here](#)

## Thank You Nurse Dawn

We want to send a big mahalo and a hui hou to Dawn Enfield-Kunewa, the RN Coordinator at the HTC, as she heads on to new adventures. Thank you for all your care and support, and best of luck in your future endeavors!



## Women & Girls with Bleeding Disorders Summit



Click the photo to learn more & register!

Registration is now open for the 4th WFH Global Summit on Women and Girls with Bleeding Disorders (WGBD)! Taking place virtually on September 25 to 26, 2025, this two-day event will bring together people with bleeding disorders, families, healthcare providers, national member organization (NMO) advocates, and other stakeholders for a global exchange of knowledge, lived experience, and best practices.





**Hawaii Chapter**

NATIONAL **BLEEDING DISORDERS** FOUNDATION

July 29, 2025

Aloha,

The Hawaii Chapter of the National Bleeding Disorders Foundation is a 501(c)(3) nonprofit organization serving people with Hemophilia, von Willebrand disease and other bleeding disorders throughout the state since 2016. HI-NBDF provides educational programming and support services for families within all the islands in Hawaii, helping those affected lead healthy and normal lifestyles. HI-NBDF works with national organizations and industry partners to improve healthcare, support research, and provide necessary resources for the bleeding disorders community, free of charge.

We will be hosting our 1st Annual Virtual Silent Auction throughout October 2025 (launching on the 1st, closing on the 31st) and are looking for donations to make this a successful event! Donations can be physical item(s), or even gift/discount certificate. In prior years when it was a live event, we received resort certificates, excursion tickets, custom ukulele, artwork, jewelry, etc.

Funds raised from this event help us:

- Send families with bleeding disorders to family camp, teen retreats, and even to Capitol Hill in DC to advocate on behalf of the bleeding disorders community.
- Deliver educational programming during events such as family camps, retreats, and educational weekends.
- Provide financial assistance for those in need.

We would appreciate your response by September 19th, 2025, for proper acknowledgement. HI-NBDF is a 501(c)(3) non-profit organization, so your donation is tax deductible as well.

As a token of our appreciation, your organization will be recognized on the online platform, on our social media accounts and in our fall and winter newsletter released in October and January. Your favorable consideration and your generous support are greatly appreciated so that we can continue to support educational and community assistance programs.

If you have any questions, please contact me at any time.

Mahalo for your time and consideration!

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