



Hawaii Chapter

NATIONAL BLEEDING DISORDERS FOUNDATION

E-NEWSLETTER
ISSUE III



2024

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2024 Unite Walk

This year was our 9th annual Unite Walk in Hawaii! To date, we've raised \$13,795 made up of 16 teams and 70 registered participants. We haven't reached our fundraising goal yet, but please keep in mind that we still collect funds throughout the entire calendar year! With this in mind, hopefully we can be closer to our goal when the end of the year comes around.

Making Connections

I was so excited to be back at our Unite Walk event this year since I was unable to attend last year due to being in Kapi`olani Hospital. This year thanks to one of our community members, we got in contact with Hiki No Transport. They were super easy to work with and supplied all the tents, tables, and chairs for us for under \$1,000 which saved our chapter soo much!! To put into perspective, last year, we paid almost 4x that price for just about the same order. I love saving our organization money wherever I can, so I am so thankful that connection was made.

We also hired a DJ this year which was new for us, and got a lot of good feedback! His name was Andrew Aragon and is on Instagram under @theandrewaragon if you are interested in hiring him for an event. This was actually the cousin of someone I went to college with so another example of using connections for events! He was also very easy to work with and cost effective, so another company we highly recommend working with.

Our last hired outside entertainment was Storybook Entertainment who we have used at walks in the past. This year, we had a face painter come and join us and she was a big hit! At one point there was a line of kids waiting to see her- even some adults joined in on the fun!

Prize Winners

This year, we had 4 Factor Club members: Robert F, Josiah H, Ashley P, and Ann O. You become a part of this exclusive group by raising at least \$500. Cynthia from Sanofi helped me recognize these amazing achievers by presenting them with Kukui Nut Lei. You may notice that this is different from previous years where you have received the Factor Club Medal. These medals will be sent to our recipients in the mail, along with their selected prizes. What prizes you ask? This year, our fundraisers were given the choice between two different prizes for each fundraising level.

2024 Incentive Items

\$250 - \$499	\$500 - \$999	\$1,000+
 Unite belt bag or Unite lunch bag	 Unite pet leash or Unite 2-in-1 fan and phone stand	 Unite cooler backpack or Unite bluetooth speaker
		

2024 Unite Walk



For the \$250-\$499 category, our prize recipients were Jennifer C and myself. The next category is \$500-\$999 and those recipients were Robert F and Josiah H. The top fundraising range was those who raised over \$1,000 and we had two recipients in that category! Congratulations to Ashley P and Ann O for each raising more than \$1,000 on their individual walk pages!

Ashley P was also the recipient of our top team captain award and she gets a fleece Unite Walk jacket in her preferred style and size!

If you remember reading my Walk e-mails, you might remember the competition we had that ran for the last few weeks leading up to Walk day. For every \$250 raised on your walk page during that time frame, you had an entry placed into a luck-of-the-draw pull. Our winner was Jen C and she won a gift certificate for two guests aboard the Body Glove Ocean Adventures Deluxe Snorkel & Dolphin Watch worth \$365.

Congratulations to all our winners! I hope everyone who was able to attend had a great time and for those who weren't, we are planning on having our Unite Walk in December next year following December Voices so that outer island families are able to join us!

Please remember that we are continuing to fundraise throughout the year so just because the Unite Walk event is over, does not mean our fundraising efforts need to stop!! Support the chapter by donating to the Walk [HERE](#).



Pie Fundraiser

We are looking for alternative sources of fundraising to supplement our expenses throughout the year without having to rely on pharmaceutical sponsorship and one of those ways is we are selling Holy's Bakery Pies! Flavors are apple, pear, coconut, and peach. If you are not familiar with this company's pies, they are out of Honoka`a on the Big Island and they are sold frozen with slices of butter under the crust so that when you take it home and bake it, that butter melts under a flakey crust and it is AMAZING! Probably not doctor recommended, but definitely tastebud recommended!

We are selling these pies for \$20 each. They retail here in Kona for about \$28 or \$24 if you can catch it in the ad. Apparently, they've been found on O`ahu for \$30 and as much as \$36 on Maui! \$20 is definitely a great price for these pies and we are opening orders to all islands!

If you have not done so already, please help us out by printing out our sign-up sheet and collecting orders from family, friends, neighbors, etc! Preliminary orders are due Nov 5th and final orders are due Nov 12th! Pies will be picked up on Tuesday Nov 26th and shipped out to the outer islands that day! There will need to be a few people to pick up orders from cargo that day and everyone who ordered will need to arrange to pick up their orders, or have your buyers pick it up themselves.

I do have someone that works for Aloha Air cargo that I was going to use to help us ship but they have some health issues right now and I would prefer not to bother them with this request if I don't have to, so if anyone else has any connections to someone who could get us a discounted price to ship out these pies, please let me know! Someone who also has their own boat that wants to take a trip to a different island works as well haha.

Again, preliminary orders need to be sent to by preferably by end of day Nov 4th so I can submit on the 4th, and final orders sent to me by end of day Nov 11th so it can be sent in on Nov 12th.



Pie Fundraiser

During our most recent town hall meeting, I had told our national staff that we are doing this wonderful fundraiser. One of our National Staffers suggested that those who are in the states who want to support can donate money to purchase a pie, and then we can deliver them to local shelters! Within the first 15 minutes, we got 7 pies donated from 3 amazing National Staffers: Renee Peck- Senior Director of Development, Chelsea Hilty- National Chapter Operations Coordinator, and Dawn Rotellini- Chief Operating Officer.

If you are interested in donating a pie to a local shelter this Thanksgiving, please send me your pie orders! We would love the chance to have our organization give back!



Explore Head-to-Head Pharmacokinetic (PK) Study Data

See half-life, clearance, and other PK data from the crossover study comparing Kovaltry® and Advate®.

Visit [Kovaltry-us.com](https://www.kovaltry-us.com) to find out more.

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Antihemophilic Factor (Recombinant)

Kahala Mall Fundraiser



Join us for the 11th Annual Very Merry Event – 3-DAYS of mall-wide holiday shopping with exclusive discounts for ticket holders only! Tickets are \$5 each with 100% of the proceeds coming directly to our organization.

Your favorite Kahala Mall merchants are supporting this event: Fighting Eel, Soha Living, Surf Camp, Whole Foods Market and more! Ticket holders will also enter-to-win a (1) night Staycation at the Kahala Hotel & Resort w/ a breakfast for (2) at The Plumeria Beach House! Plus, (5) lucky winners will receive a \$100 Kahala Mall Gift Card! (Entry box will be located in Center Court on Dec. 13-15. Forms will also be available, no purchase necessary. Must be 18 years or older to enter.)

Please find the list of vendors and their deals on the following page!

Participating Stores & Restaurants:

(Scan QR for mobile listing of the Merchant Offers)



33 BUTTERFLIES

30% OFF (1) reg. priced Brook x Willow or Spoken Label brand item (\$30 min. purchase).

ADORE

30% OFF (1) reg. priced item. Excludes Aloha Collection.

ALOHA SALADS

FREE sm. drink w/ min. \$10 purchase.

CALISTA

25% OFF (1) reg. priced item.

CAROUSEL CANDYLAND

(1) FREE sm. reg. icee w/ min. purchase \$25 or more.

CHAYA HAWAII

10% OFF all items including gift cards & apparel.

CLAIRE'S

20% OFF min. \$40 purchase. Excludes ear piercings.

COCONENE

20% OFF (2) or more reg. priced made in Hawaii products. 40% OFF clearance.

THE COMPLEAT KITCHEN

15% OFF (1) reg. priced item. (One per person, per ticket, per day. All sales final).

CONSOLIDATED KAHALA THEATRES

Buy a \$25 or more gift card, get a FREE Lg. popcorn voucher, while supplies last. Combinable w/ other offers.

THE COUNTER CUSTOM BURGERS

FREE small fries w/ purchase of a 1/3 lb. burger. (Limit (1) per table).

DIAMOND HEAD CHOCOLATE

20% OFF entire purchase.

EAGLE NAILS

10% OFF any service. One-time use, only at Kahala location.

EUROPEAN WAX CENTER

Purchase (9) Services, get (3) FREE or purchase (1) year unlimited, get 13th month FREE.

THE FACESHOP

20% OFF (1) reg. priced item. Valid on select brands.

FIGHTING EEL

10% OFF (1) reg. priced item. One time use only.

GNC

20% OFF (1) reg. priced item.

GOMA TEI

(1) mini mapo tofu rice for \$5 w/ purchase of \$25.

IN MY CLOSET

25% OFF (1) reg. priced item.

JAMBA HAWAII

20% OFF any (1) food or drink item.

JEANS WAREHOUSE

30% OFF (1) reg. priced item.

KURUKURU SUSHI

10% OFF entire order.

MAGNOLIA

20% OFF all holiday decorations.

MAHINA

15% OFF (1) reg. priced item. All sales final.

MARSHA NADALIN

SALON + SPA
20% OFF (1) reg. priced retail item.

NOHEA GALLERY

10% OFF 16 x 20 custom prints;
5% OFF Jeff Chang ceramics.

PACIFIC OCEAN JEWELERS

25% OFF (1) reg. priced item.

PANIOLOS HAWAII

FREE sm. drink w/ min. \$10 purchase.

THE PAPERIE

20% OFF (1) reg. priced item.

PEARL'S KOREAN BBQ

FREE (4) piece fried mandoo w/ purchase of any plate.

PICTURES PLUS

20% OFF custom printing (min. \$100 purchase). Excludes framing.

PIZZA HUT

\$7.99 each: 2 Pizza Melts, Mix & Match. Available in-store & online-delivery charges will be applied. (Kahala Mall location only).

PLUS INTERIORS

20% OFF all furniture pieces.

PRETZELMAKER

FREE sm. soda w/ min. \$25 order.

PURE BARRE

\$79 first mo. of classes (Gift Certificate available). 20% OFF retail items.

THE REFINERY

20% OFF (1) reg. priced item.

REYN SPOONER

15% OFF (1) reg. priced item.

SANRIO SURPRISES

20% OFF (1) reg. priced item \$25 or more.

SIMPLY HOME

20% OFF (1) reg. priced item min. \$25 purchase. Excludes Simplehuman & Eden in Love.

SOHA KEIKI

20% OFF (1) reg. priced item. Excludes sale items, lamps.

SOHA LIVING

20% OFF (1) reg. priced item. Excludes sale items, lamps.

SPLASH! HAWAII

20% OFF (1) reg. priced item. Some exclusions apply.

STRETCH LAB

\$75 OFF (3) pack of 50 min. stretch. (One per customer, Kahala location only).

SURF CAMP

20% OFF storewide, restrictions apply.

T&C SURF DESIGNS

30% OFF (1) single full priced T&C brand apparel or accessory item.

TACO BELL

FREE med. drink w/ min. \$6 purchase. Available in-store at Kahala Mall only. Not valid online, kiosk, delivery.

THINKER THINGS

30% OFF (1) reg. priced item.

THINKER TOYS

30% OFF (1) reg. priced item.

UNCLE SHARKII POKE BAR

50% OFF boba milk tea w/ purchase of a poke bowl.

UP & RIDING

20% OFF storewide, restrictions apply.

WHOLE FOODS MARKET

FREE reusable bag w/ \$75 purchase, while supplies last!

Restrictions apply, visit each participating store for details. Does not apply to previous purchases, cannot be combined with any individual merchant offer. No substitutions, rainchecks or cash value issued. Offer may only be used once at each participating merchant. Visit KahalaMallCenter.com for details.



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.*

 | 

UPCOMING

We have more events coming up for you to take part in! Register for all of the great events [HERE.](#)

1) November 1

Hilo Education Dinner with Medexus

Hilo | 6:00PM

- Join us for a beautiful night in Hilo as Medexus presents their talk on....

2) November 11

Annual Golf Tournament Fundraiser

The Club at Hokuli`a

- We are just about full for our golf tournament this year! We currently have ____ golfers which is very exciting! We are thrilled to be back at Hokuli`a this year and have the opportunity to play on this amazing private course. There will be a silent auction during lunch and an awards reception after play so if you have anything you want to donate to our silent auction, or know of a company we can reach out to for donations, please let me know! We are also working on finalizing our food vendor for that day and would love suggestions! All proceeds from registration and silent auction will stay within our chapter to be used towards resources and education for our Hawai`i families!

3) December 13

O`ahu Education Dinner with Sanofi

O`ahu | TBD

- Sanofi will be hosting an ed dinner the night before December Voices on O`ahu. Exact venue location, time, and topic TBA. Stay up to date with any changes by checking our calendar of events page on our website [HERE.](#)

4) December 14

December Voices

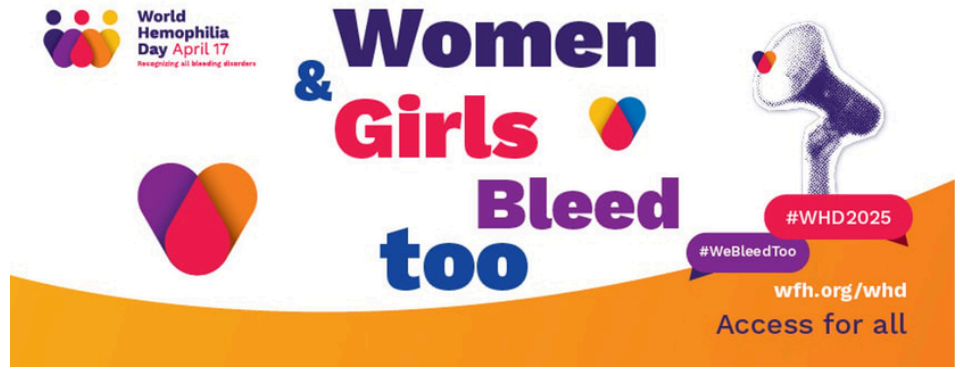
TBD

- Join us to wrap up the year by celebrating all our wins and being together to enjoy each other's company. We have so much fun planned for December Voices this year and we can't wait to see you all there. Tentative location will be at the Convention Center. We will have our COO Dawn Rotellini join us, as well as Nikole Scappe-Hagen, Manager of Education and Bill Robie, the Senior Director of Government Relations. We will also have a presentation by Hanna Berry who now works for Believe Limited, but used to work for the Colorado Chapter, so has many years of experience in "chapter land." I have something special planned for the kids so if everyone can **register by November 29th**, that would be greatly appreciated.

You can learn more and register for these events [HERE!](#)

WFH Announces World Hemophilia Day Theme

On October 1st, the World Federation of Hemophilia (WFH) announced the theme for the 2025 World Hemophilia Day, "Access for All: Women and Girls Bleed Too".



The 2025 theme addresses several key issues:

- **Underdiagnosis:** Many women and girls with bleeding disorders go undiagnosed or face significant delays in diagnosis due to misconceptions about the prevalence of these conditions in females.
- **Inadequate Treatment:** Even when diagnosed, WGBDs often receive suboptimal care compared to their male counterparts.
- **Lack of Awareness:** There is a general lack of awareness about how bleeding disorders manifest in women and girls, both among the public and healthcare providers.
- **Impact on Quality of Life:** Undiagnosed or poorly managed bleeding disorders can significantly impact the quality of life for women and girls, affecting education, career, and personal relationships.

For more information on World Hemophilia Day 2025 and how you can get involved, visit WFH's website [HERE](#).

Open Enrollment Starts Nov 1



Open enrollment is the time period where you can sign up for health insurance or adjust your current plan. Open enrollment through the Health Insurance Marketplace begins November 1st and ends January 15th, so make sure you are ready if you plan to make any changes. Learn more [HERE](#).