



Hawaii Chapter

NATIONAL BLEEDING DISORDERS FOUNDATION

E-NEWSLETTER
ISSUE I



2026

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State Advocacy Day

State Advocacy Day was scheduled for February 9th with an educational dinner training on the 8th. Unfortunately, due to weather, a call was made Sunday afternoon to close state offices on Monday so we were not able to go through with office visits at the capital. We will continue to incorporate advocacy in our future programming and plan for next state advocacy day. Mahalo to Bill Robie who flew out from Oregon to help guide us through the world of advocacy, and to Takeda who was supposed to sponsor dinner on the night of the 8th.

Ohana Education Weekend

At the end of March, we held our annual Ohana Education Weekend event. I was not in attendance due to a family event that was the same weekend, but we had Stephanie Dupree from the Nevada chapter and Kenneth McElderry from national fly in to facilitate the program! Here is what Stephanie had to say about the program:

"Ohana Education Weekend was almost blown away by the Kona Low, but we still managed to come together as a community for education and new memories. On Saturday March 21st, 25 community members from 3 islands, 3 HTC staff members, 18 medical industry representatives, and 2 NBDF staff members all gathered at the Hawaii Convention Center. We welcomed new families and caught up with long time friends. Topics of conversation included planning the upcoming HI Unite for Bleeding Disorders Walk, how to get involved in advocacy and leadership development programs offered to bleeding disorder families at the national level, and meeting the new staff members from the HTC. An education presentation about VWD and Women's health was especially well received, and we learned about multiple new therapies and products for patients. Mahalo for all your patience and flexibility as we planned around the flooding and rain that weekend!"

A big mahalo also to Stephanie and Kenneth for holding it down! Also, mahalo to our sponsors:

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Bleeding Disorders Conference Interest

Just a reminder, if you are interested in attending the annual Bleeding Disorders Conference this year which will be taking place in Florida on August 13-15, please be sure [fill out the form](#) by May 5th. This is for those who are INTERESTED in attending. It DOES NOT GUARANTEE your attendance at event. After that, there will be a process to pick who will be traveling to the conference on behalf of the chapter. Please do make sure prior to putting your name down that you have those dates available/no prior commitments. Also, huge congratulations to Zack who will be speaking on a panel there, and to Josiah and Serenidee who are recipients of NBDF's travel stipend program!

Unite Walk/Community Voices Date Change

There was a poll that recently went out to decide the NEW date of Unite Walk and Community Voices. The poll has since closed but the date that got the most votes was the weekend of October 24th / 25th so please make sure you have those dates marked in your calendars! Links to register and create your walk page are on the chapter website calendar at hi.bleeding.org.

Unite Walk

Our chapter's Unite Walk page is up and running! If you have not done so already, please register and make/reactivate your account! Funds raised help keep our chapter running and keep our programs free to our community members. Even if you are not able to make a self donation, you can share your link to your page on social media pages or send them through a text to family and friends!

At the end of this newsletter is a mock poster of a fundraising idea that you are more than welcome to borrow. The idea is that you would offer to your neighbors, friends, and family, that you're fundraising to meet your Unite Walk goal and instead or in addition to traditional donations, you can ask them if they are willing to donate their recyclables to you and in return, you recycle them for cash and use that money to put towards your fundraising goal. If this is something of interest to you, please reach out to Kyra to get the flier personalized to you.

As a reminder, the incentive items being offered this year are on the next page.



Register Here!



2026 Incentives

\$25+
T-Shirt



\$250-\$499
Fleece Roll-Up Blanket



\$500-\$999
Dad Hat



\$1000+
Fleece Crewneck Sweatshirt



Tom Team
Captain Award



\$500+
Factor Club Metal



Artwork Needed

Are you an artist? Or just like to draw? We could use your help! The HTC just moved into their new office and has a bunch of blank wall space that we thought would look great filled with our community members artwork! We are also looking to have some art pieces made around different chapter events that we can share through our social media pages, website, and newsletter! Maybe draw something that you're able to do because of the help from your amazing HTC care team like play sports, go on a hike, or just a picture of you and the staff! Are you into photography or another medium? We could feature your artwork as well!

Connections

Do you have a connection to someone who could help the chapter? Right now, we are looking for

- Polynesian Cultural Center Tickets for Teen Camp
- Bus Rental
- Silent Auction/Golf prize items
 - This can look like gift certificates/cards
 - Assorted gift basket
 - Hotel stays
 - Excursion tickets (whale watching, helicopter tours, zip line, etc)
 - Beverage donations for Golf
 - Food donations (pastries, snacks for golfers or to be put into gift basket
 - Other items we got in the past included things like coolers, jewelry, art pieces, baby gear, musical instruments, power tools, etc.)

Celebration Center!

This is a little segment I would like to keep in our quarterly e-newsletter where we get to celebrate those in our community through different milestones and special events!



`Ano`i Cadirao

Welcome to the world `Ano`i Hala`iokekai Cadirao! On February 16th, Aulani and Nolan welcomed their newest addition to their ohana `Ano`i, weighing in at 7 lbs 8.6 oz. Baby is now at home getting all the loves from mom, dad, big sister `Auli`i, Mimi and PopPop!



Grace Holomalia-Mulu

"We are honored to share that Grace has been accepted to attend CSL Behring's Gettin' in the Game Junior National Championship in Henderson, Nevada. Grace will be competing in swimming, and we are so grateful for this opportunity. For a long time, women were often overlooked as "just carriers" of the gene; however with the recent shift in recognizing that carriers who exhibit symptoms are mild hemophiliacs themselves, Grace is especially proud to represent our Hawai`i chapter. She is excited to head to the competition not just as a carrier, but as a hemophiliac athlete. We will be departing Hilo on Thursday, April 30th, and returning Sunday, May 3rd and we can't wait to share her experience with our community!" -Lauren



Celebration Center!

Mason Holomalia-Mulu

"Hi, My name is Mason. I am 14 years old. I originate from Nanakuli, O`ahu. Though I now live on Big Island. I started BUS40 Apparel around October of last year. I named it BUS40 as an ode to my home town of Nanakuli. When I lived there, I took the city bus almost every day. And the 40 bus was always the last bus I needed to get on to go home. It passed right by my house.

I currently only have one pop up under my belt. I was lucky enough to sell during Merrie Monarch week. BUS40 is a side project I do purely for fun. The money is nice too. Anyways, that's all I have to say.

Mahalo and thank you for reading." -

Mason, BUS40 Owner and Operator



Kenji Chun

"Kenji has danced with Halau Hula O Napunahaeleapua under the direction of Kumu Hula Rich Pedrina and Kumu Hula Blaine Nohara for the past 10 years. Over that time, his hula journey has come with many highs and lows, especially while living with severe Hemophilia B. From knee bleeds to a major hip bleed that left him bedridden and in a wheelchair for nearly a month- he has faced more than most ever see.

And yet, he never gave up.

Eight months ago. Kenji made the commitment to be a part of something truly special- celebrating 50 years of kane at the Merrie Monarch Festival, while honoring the legacy of the late Darrell Lupenui and the men of Waimapuna. Through every challenge, every setback, he showed up. He pushed through with strength, heart, and determination. Watching his dedication over these past eight months has been nothing short of inspiring.



This journey was about so much more than performance- it was about legacy, perseverance, the mana, the unity- it was something you could feel deep in your soul. Kenji, we are beyond proud of the man you are and the way you carried yourself each step of this journey. You are a part of something so much bigger, and it was an honor to witness it." - Jen



**HELP KYRA REACH
HER WALK GOAL!**



**COLLECT CANS &
BOTTLES TO BE PICKED
UP AND RECYCLED**

**FUNDS FROM THE RECYCLED ITEMS WILL
GO TOWARDS KYRA'S WALK GOAL AND
SUPPORT THE MISSION OF HI NBDF**

**COLLECTION WILL BE EVERY SECOND
TUESDAY OF THE MONTH**

**IF YOU DON'T WANT TO PARTICIPATE IN THE
RECYCLING PROGRAM, BUT STILL WANT TO
SUPPORT HAWAII'S BLEEDING DISORDERS
COMMUNITY, YOU CAN DONATE HERE.**



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Unite
for Bleeding Disorders