



Hawaii Chapter

NATIONAL BLEEDING DISORDERS FOUNDATION

E-NEWSLETTER
ISSUE II



2026

TABLE OF CONTENTS

3 - 4 Teen Camp a Success

5 Annual Golf tournament Fundraiser

6 Treatment Updates

7 Register for the Unite Walk

8 - 10 Koko Ohana Recap

11 Mana Wahine Women's Retreat

Teen Camp



This year, we held our first annual Teen Camp! This event was long awaited by the teens of our community, so we are glad we could finally make it happen. This camp took place June 24-26 with Koko Ohana following immediately after. We had 6 brave teens come out and test our trial year, 2 girls and 4 boys. Once we had everyone Wednesday morning, we all met at the HTC's new office location to spend a few hours with them. The teens got to role play and see what it was like being an HTC staffer for the day! Each teen got assigned a different position and went through what a typical office visit at the HTC was like. It was fun watching the kids pretend to be the medical staff, but I think Dr. Des had a better time pretending to be a teen patient! She wore her headphones, gave some sass, and even ignored the staff at times!

After our visit at the HTC, we started heading over to our campsite for the duration of the program. This year, we decided to test out a new campsite- Camp Palehua in Kapolei. The site was amazing- high elevation, cool mornings, amazing sunsets, and horses right outside the door.



Teen Camp Cont.



On Thursday, we spent the day at the Polynesian Cultural Center where the kids had fun exploring the different villages and participating in different cultural activities. Some of the kids have never been, so this was a nice treat. There were lots of laughs and lots of learning! We then had dinner at one of the buffets on site, then made our way to watch their nighttime show, Ha. This was such a great show and highly recommend everyone go watch it if they haven't already. My friend from high school has been performing in this show for years, so we were able to get everyone a backstage tour of the show! This was a great look at what goes into the production of the show.

On our last day, we started our morning cleaning up our sleep areas and getting ready to leave the camp. Once everything was cleaned, we did a low ropes course with the adult chaperones and then headed to Tropics Mini Golf. We then headed over to get some lunch in Aiea and reviewed the trip, discussing highs and lows, favorite memories, ideas for next year, and more! From there, our first teen left us to go to the airport and head back home. The rest of the teens continued their time with us at Koko Ohana.





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NATIONAL BLEEDING DISORDERS FOUNDATION

8th Year!

Annual Golf Tournament

September 28, 2026

Hokulià Golf Course, Big Island

Join us and golf for a cause as we host our 8th annual golf tournament fundraiser! All proceeds will benefit Hawai'i families with rare bleeding disorders.

Registration and Warm Ups to start at 8:30am

Announcements at 9:45am

Shotgun Start at 10am

Lunch, mini silent auction, and prizes will follow

Prizes will be given out in pairs, places being 1st, 2nd, and 8th place with 8th being the top prize to honor the 8th year anniversary.

Register at hi.bleeding.org
or contact Kyra at 808.284.7417.



Treatment Updates

Ferring Pharmaceuticals Announces Return of STIMATE

In a letter sent to healthcare providers, Ferring Pharmaceuticals announced that STIMATE® (desmopressin acetate) nasal spray is expected to be available in the United States beginning October 2026.

STIMATE was [voluntarily recalled in July of 2020](#) due to a packing issue that resulted in “super-potency,” or more concentrated than specified on the label. In the letter, Ferring stated that the packaging issues have been resolved and it has received approval from the US Food and Drug Administration (FDA). The company expects that it will be available through wholesale and retail pharmacies in October.

NBDF is working to gain more information about the availability of STIMATE in the US, including how it will be distributed, its inclusion in formularies, and any other relevant information that could impact people’s ability to access the treatment. We will provide updates as soon as they become available.

STIMATE can be used to treat people with hemophilia A and mild to moderate von Willebrand disease. For the full prescribing information, refer to the letter from Ferring below or visit [Ferring’s website](#). If you have questions about your specific treatment, please consult your healthcare provider.

[Read the complete letter from Ferring.](#)

First-Ever Recommendations Call for Routine Iron Screening in People with Bleeding Disorders

Iron deficiency, with and without anemia, is the most common micronutrient deficiency around the world. People with bleeding disorders have a higher risk of developing these conditions due to blood loss from bleeding episodes. Until now, there were no standardized guidelines for screening for iron deficiency in people with bleeding disorders. That has changed with the release of NBDF’s Medical and Scientific Advisory Council’s (MASAC) new recommendations that give doctors and other clinicians clear guidance on how to address this issue.

[The recommendation](#), which is available in full on NBDF’s website, recommends that all individuals with an inherited bleeding disorder, including hemophilia, von Willebrand disease, rare factor disorders and platelet disorders, be routinely and periodically screen for iron deficiency and anemia irrespective of sex, age, or bleeding disorders severity. Further, the document recommends a multidisciplinary approach to laboratory testing for iron deficiency and anemia, “including collaboration between primary care providers and specialists to ensure timely diagnosis, monitoring, and resolution of iron deficiency.”

When considering the need for the recommendation, MASAC found that only 4% of 10,527 females with bleeding disorders had been screened for iron deficiency yet 72% of the of the individuals met criteria for iron deficiency. This, along with other studies cited in the MASAC document, shows that prevalence of iron deficiency is significantly underestimated.

[Read the full article.](#)



Unite

for Bleeding Disorders

SUNDAY, OCTOBER 25

ALA MOANA REGIONAL PARK

The Walk is a nationwide fundraising and awareness campaign to support the Hawai'i Bleeding Disorders Community.

2026 INCENTIVES



LEADER BOARD



Elizabeth Pulley
\$203



Reina Vega
\$105



Zack Stein
\$103



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\$100



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\$25

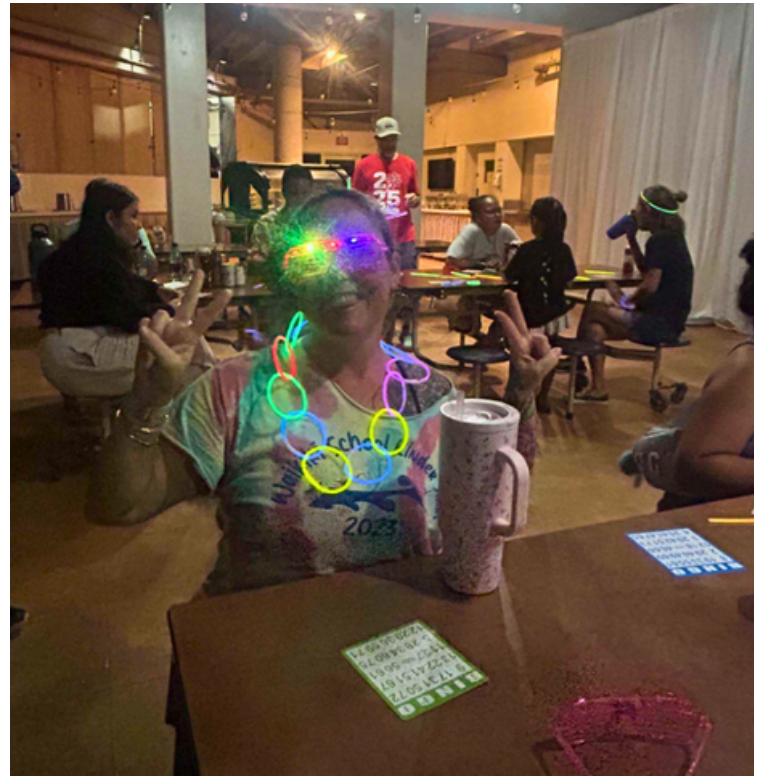


Jessica Anub
\$103

THANK YOU EVERYONE!

Koko Ohana

Following the conclusion of Teen Camp over lunch, we took the remaining teens with us up to Camp Mokule`ia. Once there, they helped unpack vehicles with program supplies and get families situated in their cabins. Once everyone was settled, we ate dinner, followed by a presentation by one of our Platinum sponsors, Octapharma. During that session, we started to set up for Disco Bingo! The teens and kids helped us prepare the space and set the mood. Once families moved in for Disco Bingo, two of our teens Mason and Lucas took it upon themselves to volunteer and lead the activity, and they did an amazing job! They kept it exciting and entertaining.



After breakfast on Saturday, we headed into the meeting space to start our infusion clinic which was led by some of our HTC staff: Dr. Des, EJ, Lauren, Jason, and Robert. This year, we purchased fake arms to practice infusions for those who were not comfortable poking themselves. We had both pediatric and adult fake arms for those who may have younger children they might want to practice for. We had many people practice on the arms which was great! The more practice, the better. We also celebrated those who hit milestones at last year's camp: Cameron with the Big Stick Award and Bella, who stuck herself but was still practicing getting the 'flash'. In addition to those awards, we also gave additional out to Kenji and Xochitl who both earned their Big Stick Awards! Congratulations to all those who were brave enough to try/keep trying and will hopefully influence others to do the same!

Koko Ohana Cont.



EJ also had an amazing art project prepared for everyone. She has a bunch of canvas tiles taped together, making up one large drawing she created to be put up at the new HTC location. Each person was to take a tile and color it, creating a bunch of mini custom pieces to make up the larger picture! Such a neat idea, and we will be sure to post a picture of it once it is completely finished!

Following that activity, we had Bloom and Morgan with GutMonkey come and to a pre-excursion activity with our community members. They got water bottles, stickers, and even got to make their own trail mix at the BIY trail mix bar! This was such a cool idea and definitely think we will be doing it again in the future. We then loaded a bus and all headed over to Waimea Falls to start our excursion and hike. During the bus ride, Bloom lead an activity where we identified different bags of items and how that may be useful to us on the trip. We also nominated a teen to be in charge of a scavenger activity during our time at Waimea Falls. During our time at the falls, we got to stop at a bunch of the different activities. Once at the falls, we took a large group picture and then had the rest of the time to swim and make our way back down. We had over 2 hours of swim and free time before having to head back down and I know many people appreciated having that time to relax and cool down.

Once we made our way back to the bus and back to camp, everyone was exhausted from the hike and hot weather so we had free time until dinner. A group of us chose to spend that time cooling down (again) in the ocean right in front of the cabins. We then all made our way over to dinner, followed by Campfire. There, the HTC staff and Nikole led a bunch of campfire songs to get the group pumped up. I know the HTC staff was practicing for a while leading up to the campfire so that they were prepared for the campers. We then started s'mores, a campfire staple. This year, we changed it up by buying chocolate covered cookies instead of separate crackers and chocolate. This was soo much more efficient- huge shoutout to Nikole for suggesting!

After campfire, a group of kids went down to the shoreline to catch crabs, another camp staple activity. Others joined us up by the cabins as we blew up the inflatable screen and started Lilo & Stitch Live Action. By the end of the night, everyone was absolutely exhausted and worn out and we were all happy to obey quite hours once 10pm rolled around.

Koko Ohana Cont.

On our last day, we started with breakfast, then jumped right into 3 sessions. The first was a goal setting activity with Heather from NBDF. This seemed like a very beneficial session, even the industry partners were participating. Everyone can use some life evaluation and reset. Following this session, our other platinum sponsor Sanofi came up and presented to our community. We finished our last session with a teen panel. The teens got to share in front of their parents what they learned over their time together at Teen Camp, what they're looking forward to, and their favorite memories! This was a great way to showcase all they learned and did together.

Concluding this, we updated on our upcoming organization programs and then started seeing each other off. We did change up a few things this year at camp, but I do think that this worked out better than previous years, and I think our community would agree.



Thank You Sponsors

Platinum **octapharma®** **sanofi**

Diamond **CSL Behring**  **InfuCare Rx®**

Gold  **CVS specialty™** **Genentech**  **novo nordisk®**

 **Takeda**

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Mana Wahine

Join us September 19-20 at Honolulu for a weekend celebrating the women and girls of the bleeding disorders community.

Mana Wahine is a weekend designed just for the women of the Hawai'i Bleeding Disorders Community. It's a time to come together for informative educational sessions, fun activities, and meaningful connection as we share our experiences as daughters, sisters, moms, and caretakers. All attendees must be at least 14 years of age or freshman in high school.



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Register for this event at hi.bleeding.org or contact Kyra at 808.284.7417.

