



HAWAI`I NEWSLETTER

*Happy (Belated) Easter and World
Hemophilia Day!*

A message from Kyra

Hey everyone!

I'm very hopeful and optimistic about how 2023 will go for the Hawai'i Chapter. I am working with the board and other chapters to make sure we can make the most of this year and get the ball rolling on some events.

I am thankful for all the support from community and industry alike, and can't wait to tackle what's next. Thank you all for a wonderful 2023 so far and here's to the next quarter!

Kyra

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Congratulations Hannah!

Congratulations to our very own Hannah Marie Tokiwa for winning the title of United States Marine Corps 2023 Military Child of the Year! I am so tremendously proud of Hannah's accomplishments not only with the chapter, but in everything she does! The Tokiwa ohana will surely be missed as they move on to the next chapter of their lives outside of Hawai'i, but we can't wait to see them thrive in all they do. Mahalo Tokiwa ohana for all you have done for this chapter! We will miss you all!



Yeti 2023

We have had the great pleasure of attending Oregon's Yeti program again this year. The Oregon chapter continues to put on amazing programming and we are thankful that they take the time to include us! Yeti was held in February, and we got to take one of our teens, Isabella Linhares, as well as our Pediatric Hematologist, Dr. Dez. There were so many intricate activities planned that we stayed busy the whole time!



Isabella got to meet and spend time with other teens in the blood disorders community, and also got to teach us all Capoeira. What amazing skills! Isabella and Dr. Dez both got to reflect on what obstacles are in their lives, and how to overcome them. Part of this was tackling and facing the ropes course, which both of them did conquered! We are so thankful that they got to participate in this program and represent the chapter. We can't wait to collaborate on how to improve our local programming.



Ohana Education Weekend

This year's Ohana Education Weekend was held on March 25-26th at the Hyatt Regency Waikiki. We had such amazing feedback from both community members and representatives. For this being my first larger event on my own, I am thankful for community members and volunteers alike that weekend who have helped me with setting up, cleaning up, and everything in between. We had the wonderful University of Hawai'i Baseball head coach, Rich Hill, come and be our Keynote speaker. He was such an amazing presenter and motivator.



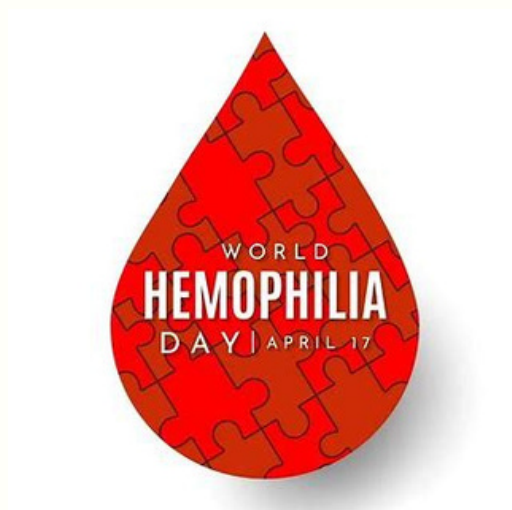




We had a handful of educational sessions, as well as some new activities where you had to be moving around (hotel scavenger hunt, and industry round tables). A big mahalo to our teen volunteer and junior board member Hannah for stepping up and assisting with the scavenger hunt, as well as coming up with fun activities for the kids to keep them entertained during sessions. Of course, this program would not be possible without the generous funding from our sponsors Sanofi, Takeda, Accredo, CSL Behring, Octapharma, Bayer, BioMarin, CVS, Genentech, HemaBiologics, Pfizer, and Westside Specialty Pharmacy. Thank you for making this event possible and for continuing to support Hawai'i's blood disorders community.

World Hemophilia Day

Happy (belated) World Hemophilia Day!

Aloha Tower on O`ahu was lit up red last night in honor of World Hemophilia Day. We try to make this an annual occurrence, so save the date for next year!






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)

Unite Walk

QR code to Chapter Walk Page



We are planning on holding our Unite Walk in October again. We are confirming venue and dates so we will officially announce all information once everything is confirmed.

Currently, we have 30 participants and 11 different teams. We have \$1,150 raised out of our \$30,000 goal. It is still very early, so I am hopeful that we can start adding to our funds soon!



- TOP FUNDRAISERS**
- Ann Okahara
 - Rod Calbero
 - Jeannine Gomez
 - Carol Yamamoto
 - Deb Calbero
 - Kyra Calbero
 - Amanda Tokiwa
 - Cameron Chin
 - Carmen Linhares

2023 UNITE WALK (Honolulu, HI)

[REGISTER NOW!](#) [DONATE TO THIS EVENT](#)

Event Details

Where	Kapiolani Park Honolulu, HI
Starts	10/07/2023 @ 8:00 AM
Ends	12:00 PM
Check-in Time	7:00 AM to 8:00 AM
Registration Cutoff	10/06/2023 @ 11:45 PM
Donation Cutoff	12/31/2023 @ 11:45 PM



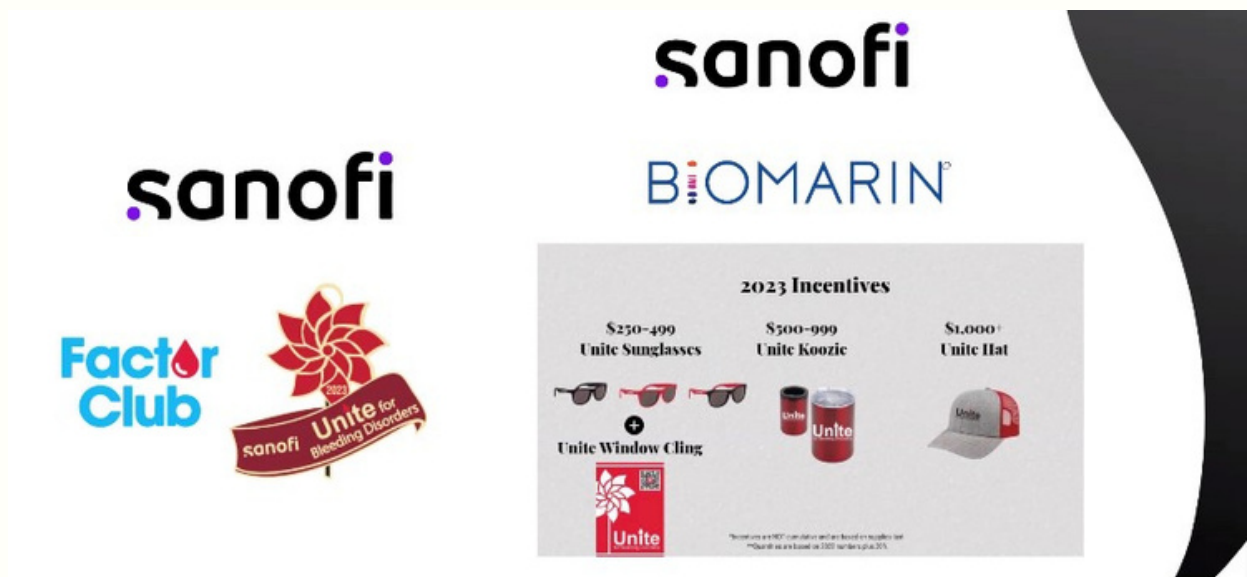
[Register for our walk here!](#)

Once you create/reactivate your existing profile, there is an option to create a Facebook fundraiser. This is such a quick and easy thing you can do that will allow your friends to donate to your walk without you having to ask everyone.

Another great tip is to add pictures of bleeds, injuries, and infusions to your posts with donation links. Seeing what some of our families go through may pull at heart strings and motivate friends and family to donate.

A self donation of \$25 to your own walk page gets you the Unite t-shirt. Other incentive items are pictured on the right. The following are for overall total made on your walk page:

- \$250-\$499 gets you Unite Sunglasses and a window cling.
- \$500-\$999 gets you a Unite Koozie
- \$1,000+ gets you a Unite Trucker Hat
- Any amount collected over \$500 will get you a Factor Club medal but please note that the other incentives in the grey box are 1 per walk page. (If you got \$750 total, you would receive the koozie and the Unite medal, not the glasses, koozie and medal)



This year's top team captain prize is a nice North Face waterproof jacket with the Unite logo on the front so make sure you are a team captain to be eligible for this prize!

**Takeda:
Top Team Captain Prize Sponsor**



This year, they are also offering incentives for board members! If you are a board member, you are eligible to win the prizes on the right.

Board Incentives

Top Board Fundraiser 1 per Chapter

Every Board Member who raises \$100 or more gets entered into drawing 1 per Chapter

Just a reminder that all donations and funds raised stay within the Hawai`i Chapter to help our local families. These funds help pay for family camp, flights, hotel and transportation, food, all our fun activities, venues, financial assistance, and more!

If anyone is interested in donating goods instead of money, please let me know and I can send you a donation form. Some donation items we are looking for in specific are breakfast items (pastries, coffee), snacks (chips, granola, candy), drinks (water, juice, and soda), equipment sponsor (AV, tents, tables, chairs, decor), and any form of entertainment (musicians, characters, dance, face painting, bounce house, kids play area, etc)

Happy Fundraising!!

Generation IX Project

If you are an individual with Hemophilia B, there is a wonderful mentorship opportunity available to you! There are two separate programs, one for adults and one for teens. I have personally done the adult program before and it is such a wonderful experience. I did it virtually during covid, so now that it is back in person, I can only imagine how amazing the programming and experience will be! Applications are due by the 25th of this month!

MENTORSHIP EXPERIENCE
Folks with hemophilia B age 13 - 35

GENERATION IX PROJECT

Adult: June 6-11
Teens: June 8-11

Participation and travel at no cost to you

Learn more at gutmankey.com/generationix-hemob.org/
Apply at app1.generationixproject.com

Young adult mentor volunteers engage in a state of the art, experiential training and then welcome new participants to an ancient Oregon forest for an epic weekend they'll never forget. Fund local groups and be together your hemophilia B community across the nation. Learn invaluable skills about living with hemophilia B and finding your way in the world.

THE CONSORTIUM FOR HEMOPHILIA
MEADOX PHARMA
GUTMANKEY

APPLY BY APRIL 25! gen@gutmankey.com
contact@hemob.com
factorxlabmeadox.com

WBDR Now Enrolling People with VWD

Good news! People with VWD can now enroll in the World Federation of Hemophilia's World Bleeding Disorders Registry (WBDR) . This will help strengthen evidence to provide better care for individuals with VWD worldwide. [Join the registry](#) today in the efforts to collect data globally to enhance research and advocacy! *Please note that individuals with Hemophilia are already eligible to enroll.

Upcoming

We are in the works of creating a women's, men's, and teen retreat this year. This is something new for myself so please bear with me as I work on all the details of adding new programs to our calendar. I am excited to get these programs setup for our chapter, and hope to make it an annual event.

Of course, we have Koko Ohana coming up at the end of June. If you are planning on attending and have not registered yet, please make sure you [register](#) as we have a registration deadline of June 2nd. No late registrations will be accepted.

Golf location and dates are still being finalized. If you want to play/make a team, I can send you the different sponsorship levels. If you don't want to golf, but want to help in other ways like donations, I can send you a donation form. Some donation items we are looking for are the same food items listed for the walk, with the addition of beer. We are also planning on having a silent auction at the golf event so please keep an eye out for any businesses who may be willing to donate, or if you have something you would like to donate. Some examples we have from past years are golf clubs, golf bag, bowling tickets, Body Glove cruise, golf certificates, free hotel stays, jewelry, etc. We are open to more donations if available!

Mahalo!

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