Hawaii Chapter

NATIONAL **BLEEDING DISORDERS** FOUNDATION

E-NEWSLETTER
ISSUE I

2025

TABLE OF CONTENTS

Ohana Education Weekend

Joining us at this year's Ohana Education Weekend on April 12-13 at the Hawaii Convention Center was Jacob Murdock, Executive Director for the Nevada Chapter! He was a great asset to our programming and helped with our teens during the duration of the weekend. We also had Matthew Hartnett, Community Research Network Manager at NBDF who presented on the importance of research and areas where our community could step up and fill in. During Matthew's session, Jacob and HTC Social Worker Jason took the kids to brainstorm questions they wanted to ask the HTC staff in a session called "Stump the Staff." The kids did an amazing job at came up with over 20 questions, touching upon inheritance patters and emergency treatment.

Our kids also got the opportunity to participate in photo bingo, camp theme planning session, and even an Easter Egg hunt! We had some great ideas about different camp themes, as well different games and activities that we could do that would relate to the theme. Our adults also got to hear presentations from Octapharma, Novo Nordisk, and Takeda, Platinum Sponsors for this year's event.

For lunch on Saturday, we took a little stroll over to Ala Moana food court, where we had many more options for lunch! This was a great alternative to our usual food order through hotel. Not only did it save us a whole lot of money, but it also gave us the opportunity to get out of the convention center, get fresh air, and also incorporate movement into our programming. We got a lot of good feedback regarding being off site for lunch and am hoping to make it an annual activity.

In case you missed the event, parents discussed different activities the teens/kids would like to do at Camp. We got many great ideas for programs, so now we are working on creating a sign-up sheet for activity facilitation which would be a good change up for the program and kids in general.

Overall, we had a great turnout with a lot of great collaborations and are so excited to continue to provide programming to you all!

Mahalo to our Ohana Ed Weekend Sponsors

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Ohana Education Weekend

Staffing Announcement

In case you missed it, in January of this year, Kyra Calbero took on the role of Chapter Executive Director. Below is the announcement that went out to all NBDF staff.

Kyra has consistently demonstrated exceptional leadership, innovation, and dedication to the mission of NBDF throughout her tenure. As Interim Executive Director and Program Manager of the Hawaii Chapter, Kyra not only ensured the success of existing programs but also spearheaded new initiatives, such as the outer island Unite Walk and an annual women's retreat, both of which have expanded community engagement and support. Her ability to navigate challenges with confidence and poise, particularly during critical transition periods, has provided stability and growth for the Hawaii Chapter, even as its sole employee for a significant portion of her tenure.

With a strong foundation in strategic planning, program development, and community engagement, coupled with national-level expertise gained through her work with NYLI and YETI, Kyra has become a dynamic and inspiring leader. Her passion for the cause and proven ability to deliver impactful results make her exceptionally well-suited to step into the role of Executive Director for the Hawaii Chapter.

Congratulations Kyra!

Advocacy Call to Action

In April, the Administration announced drastic changes and reductions to the federal health programs that support the bleeding disorders community. We are asking you to please call or email the offices your representatives and ask your lawmakers to reverse the cuts and protect funding for those programs.

What is the issue?

- On April 1, the US Department of Health and Human Services (HHS) sent termination notices to an estimated 10,000 employees.
- One of the many HHS offices that was impacted was the Division of Blood Disorders and Public Health Genomics at the Centers for Disease Control and Prevention (CDC). According to reports, all but two Division staff are expected to be terminated in the coming months.

How does this affect the Bleeding Disorders Community?

- The Division of Blood Disorders' work traces back to the 1980s' tainted blood crisis, when CDC investigators were the first to discern and warn of HIV's transmissibility through blood and blood products.
- The Division currently serves the bleeding disorders community and the nation at large through its public health surveillance activities – including maintaining a laboratory with blood samples dating back to 1996.
- It also funds the collection of key data on bleeding disorders through its "Community Counts" program and supports educational outreach to increase patient and provider understanding of bleeding disorders and their complications.
- **Elimination of the Division, its clinical repository, and its institutional knowledge would be a huge loss for the bleeding disorders community.**

What can you do to help?

It is imperative that we come together as a community and let our lawmakers know that this issue is important to us. Please take 5 minutes to contact your representatives via a phone call or email. There is a sample script on the next page that you can use when contacting them.

Senate Members

Brian Schatz
(202) 224-3934
Email him HERE

Mazie K. Hirono
(202) 224-6361
Email her HERE

House of Representatives

CLICK HERE and enter your zip code to find your member of the House and get their contact info.

Advocacy Call to Action

Below is a sample script for your calls or emails:

I am [calling/emailing] as a member of the bleeding disorders community and as a constituent to ask that you protect the federal hemophilia programs at the CDC. The recent HHS restructuring eliminated essentially all of the staff at the CDC's Division of Blood Disorders, where the bleeding disorders programs are housed. These programs:

- *Help to collect important data on bleeding disorders which in turn helps lead to new and more effective treatments.*
- *Provide funding for education and outreach to increase patient and provider understanding of bleeding disorders.*
- *Help to protect the safety of our nation's blood supply.*

I am relying on you, as my Senator/Representative in Congress, to take action to ensure that the staff for this program are reinstated and to work to protect the funding for this critical program.

Don't Forget! The bleeding disorders community has come together in the past and made great things happen. We can use our united voice again to ensure a secure future for everyone affected by a bleeding disorder.

Upcoming Events

June 20-22	Koko Ohana Family Camp
August 21-23	NBDF Bleeding Disorders Conference (Colorado)
September 13-14	Mana Wahine Women's Retreat
December 5-6	December Voices
December 7	Unite Walk

Community Voices in Research (CVR)

CVR is a community-powered registry that will help researchers understand what it really means to live with a bleeding disorder and how current treatments, therapies, and policies affect the community. It's open to all people directly affected including people with bleeding disorders, their parents, siblings, partners, and caregivers.

People who participate in CVR will share information consistently over several years through surveys, allowing researchers to better understand how bleeding disorders affect individuals and their family members across their lifespan. It will also help participants understand their individual situation and how a bleeding disorder affects their life.

By participating in CVR, you will help improve the future of people living with inherited bleeding disorders and their immediate family members. There are many ways that users directly benefit from CVR including getting a personalized dashboard to track our stats and experiences and compare them to trends of others in the community, a record that will help you when speaking to healthcare providers about symptoms and treatment options, and up to date resources like important findings and paid clinical trial and research opportunities.

Learn More and Register for CVR

Last Chance Free Trip to BDC

Win a Trip to BDC!

BDC is a 3 day event filled with educational sessions, netowrking opportunities, and exciting exhibits!

Join CVR and complete the baseline survey to be eligible.

bleeding.org/cvr

Community Voices in Research
National **Bleeding Disorders** Foundation

Register for CVR for a chance to go to BDC for Free!

The chapter also has 2 free registrations to BDC (value of $260). Participants are responsible for travel and lodging costs. Let us know if you are interested!

Unite Walk

This year the Walk will be included as part of the December Voices event, with the hopes that more community members will be able to attend.

Why is the Walk so important?

It's an awareness event- to teach people about bleeding disorders that affect YOUR loved ones.
It's a community gathering – to have fun with other people in YOUR community.
It's a fundraiser- to provide programs and services that YOU take part in.
When you walk you make a huge impact. All funds raised in Idaho stay in Idaho and are used for:

- Programs like Koko Ohana Family Camp and Ohana Education Weekend
- Emergency financial assistance for families in need
- Research into finding cures for bleeding disorders
- Advocacy at our state and national capitol

How can you get involved?

Become a Team Captain: You can make the most impact by starting your own Walk team. By becoming a team captain, you can share your personal story by letting people know why supporting the bleeding disorders community is so important to you. The more people who join and fundraise for your team, the more impact you can make!

Make a Donation: Maybe you aren't in a place to be on a Walk team this year. You can donate to the Walk or select a team and help them reach their goal.

Volunteer: Volunteer to help with a fun activity, registration, or set up.

Support the Walk here