

2023 SUMMIT REPORT



Hep B United

FAMILY REUNION: REUNITING TO END HEP B



About Hep B United & Hep B United's Goals

Hep B United (HBU) was established by the Hepatitis B Foundation (HBF) in partnership with the Association of Asian Pacific Community Health Organizations (AAPCHO) in 2012 to meet the need for enhanced hepatitis B programs and advocacy in the United States.

Since then, the coalition has continued to expand across the U.S., promoting equitable access to hepatitis B services including vaccination, testing, and linkage to care and treatment for all communities at risk for hepatitis B through evidence-based public health best practices.

The annual HBU Summit is the largest convening of hepatitis B community leaders from around the country representing patient advocates, local and state health agencies, national organizations, community-based hepatitis B coalitions, and federal agencies.

This year's theme - Family Reunion: Reuniting to End Hep B was a literal reunion of Hep B United's friends, partners, and advocates getting together in person, for the first time since 2019, to not only celebrate successes but also to discuss strategies to improve upon the work being done and reach more people around the country and world.

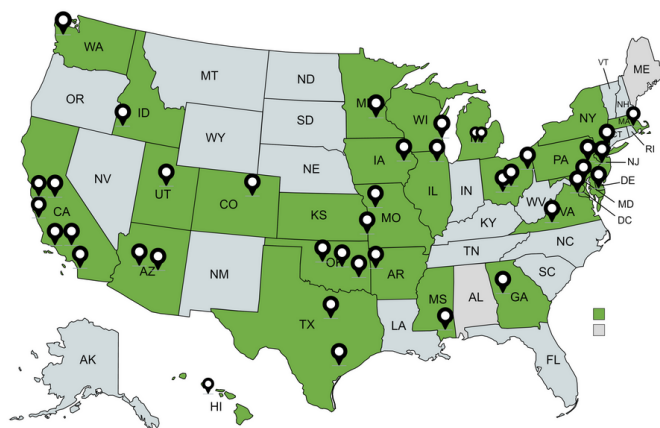
The Summit offers partners the opportunity to showcase their hard work while learning new techniques and skills that can help them advance their missions.

The goals of the Summit are to:

- Strengthen and expand Hep B United as a national coalition,
- Provide technical assistance and training,
- Promote new partnerships, and
- Foster Federal engagement on national hepatitis B programs and policy.

Overall, the Summit is a chance for collaboration, innovation, and education to help advance the three main goals of Hep B United:

- **Awareness:** Raise the profile of hepatitis B and liver cancer as an urgent public health priority.
- **Prevention:** Increase hepatitis B testing and vaccination, particularly among highly impacted communities.
- **Intervention:** Improve access to care and treatment for individuals living with hepatitis B to prevent end-stage liver disease and liver cancer.



Hep B United now has more than 55 partners in 27 states across the country! Learn more at www.hepbunited.org.



By The Numbers

Our 8th annual Hep B United Summit and Advocacy Day was held in Washington D.C. from July 24th-July 26th. The Summit brought together experts, advocates, and community health workers to share their experiences and best practices with one another.

NEARLY
100

ATTENDEES
FROM
MORE THAN **50**
ORGANIZATIONS
ACROSS THE
NATION

4

AWARD
RECIPIENTS
AT THE
COMMUNITY
RECEPTION

25

PRESENTATIONS
ACROSS
NINE SESSIONS
OVER **TWO** DAYS



Hep B United Award Recipients

Our annual Community Reception was held on July 24th at the Rayburn House Office Building. Advocates heard remarks from Representative Hank Johnson of Georgia, Hepatitis B Foundation President Dr. Chari Cohen, and AAPCHO Executive Director Jeff Caballero.

During the reception, Hep B United honored **Representative Brian Fitzpatrick** with a **Congressional Champion Award** and three outstanding hepatitis B champions for their leadership, and building an enviable legacy behind due to their tireless efforts to improve the lives of those living with hepatitis B.

The three recipients of the **Leadership Legacy Award** were **Dr. Cynthia Jorgensen, Joan Block, and Jane Pan.**



Session 1: Updates from Federal Partners

Centers for Disease Control and Prevention's Division of Viral Hepatitis

Dr. Carolyn Wester, Director of the Division of Viral Hepatitis at the Centers for Disease Control and Prevention (CDC), opened the summit by discussing the CDC's new hepatitis B screening and vaccination recommendations. These recommendations call for screening all adults aged 18 years or older at least once in a lifetime, and for vaccinating adults aged 19-59 years and adults above 60 years of age with risk factors. The shifting epidemiology of hepatitis B virus led to these changes. The CDC is providing enhanced education to patients and providers to implement these guidelines. They have resources including a summary of recommendations for hepatitis B screening, testing and vaccination by population. CDC also will be providing resources to health departments to support implementation of the new recommendations. CDC continues to support the "National Viral Hepatitis Education, Awareness and Capacity Building for Communities and Provider's," providing funds to awardee organizations that focus on populations disproportionately impacted by hepatitis B and C.



United States Health and Human Services, Offices of Infectious Disease and HIV/AIDS Policy



The Office of Infectious Disease and HIV/AIDS Policy (OIDP) released their progress report for the viral hepatitis strategic plan. Dr. Jessica Deerin, Viral Hepatitis Policy Advisor at OIDP gave progress updates. OIDP led coordination of the viral hepatitis strategic plans for elimination including the federal implementation plans. The strategic plan has eight core indicators and health disparities indicators that show progress towards meeting elimination goals in the United States, Dr. Deerin further mentioned that while they are on track for two indicators which includes reducing acute hepatitis B and reducing hepatitis B related deaths while they are not on track for four indicators which includes reducing reducing deaths among AAPI and non-Hispanic black individuals.



Session 1: Updates from Federal Partners

Update from Food and Drug Administration's Office of Minority Health and Health Equity

Dr. Christine Lee from the Food and Drug Administration (FDA) talked about the development and goals of the Office of Minority Health and Health Equity (OMHHE). OMHHE protects and promotes the health of diverse communities through research, programs, and engagement. Dr. Lee mentioned that one of OMHHE goals is to enhance equity initiatives some of which includes equity in clinical trials, equity of data (increasing disaggregated data) and equity of voices. They hope to create more funding opportunities to connect with partners, support efforts for innovation of health equity and expand educational initiatives.



Discussion from Session 1

When will the United States Preventive Services Task Force (USPSTF) officially recommend hepatitis B screening?

USPSTF's assessment is completely independent from the work that CDC conducts, so the CDC does not have any influence over whether USPSTF will choose to align their recommendations with CDC. Historically they consider updating every 3-5 years, the most recent ones were Dec. 2020. CDC and partners submitted a request for a prioritized review but were turned down. The community will request again in 2024. Once a review begins, it takes about 18 months.

How do we translate federal progress to local-level providers?

Anytime there are new recommendations, we have to raise awareness and acceptance of them by providers and policymakers. This can mean working with providers' medical associations and leadership within the health system to implement system-wide change. Policymaker buy-in can bring resources to support those efforts. Right now there is a lot of work to do in both spaces.

How can we improve primary care providers vaccinating adults for hepatitis B?

There are many challenges to ensuring adult vaccination, including: provider awareness, not having vaccine on-site, not having a trusted messenger, and cost implications. Educational outreach and service delivery can help with some of these barriers. In terms of the cost- it should be reimbursed, however, there are challenges with out-of-pocket costs for the underinsured.



Session 2: Future of Adult Hepatitis B Screening and Vaccination in the U.S.

In this session, *Michaela Jackson* from the *Hepatitis B Foundation* and *Dr. Amy Trang* from *Hepatitis B Initiative of DC (HBI-DC)* gave an overview of the new CDC Adult Universal Hepatitis B Screening and Vaccination Recommendations. They also shed some light on potential challenges that might come forth while implementing the recommendations. Some highlights from the session are listed below:

New CDC Screening and Vaccination Recommendations:

- Universal one-time hepatitis B screening for adults 18 and older. This includes a triple-panel test consisting of hepatitis B surface antigen, hepatitis B surface antibody, and hepatitis B core antibody (HBsAg, HBcAb, HBsAb).
- Universal vaccination for all adults 19-59, those 60 and older with risk factors, and anyone who wants to get vaccinated.
- Screening and vaccinating can occur in the same visit, when feasible.

Insurance Coverage for Vaccination and Screening

- With expanded coverage for vaccination, most adults should be covered with no out-of-pocket expenses.
- Insurance coverage for screening could be a challenge, but testing is typically covered.
- Future USPSTF recommendation could impact the future of hepatitis B screening coverage.

Provider challenges:

- Lack of awareness/knowledge around hepatitis B, lack of knowledge about the need for vaccination, lack of hepatitis B surveillance data, lack of buy-in from large health systems, and limited capacity of services provided.

Patient challenges:

- Low perceived risk of hepatitis B, out-of-stock vaccines, lack of awareness, screening might not be covered by insurance, complex messaging and competing priorities, and clinicians not recommending that they get vaccinated.

Priority action items:

- Educate stakeholders about the disease burden and new recommendations, explore multi-stakeholder collaborations and technology, and address vaccine hesitancy.

Strategies for implementation:

- Use appropriate messaging (vaccination/screening is routine, safe, and effective), collaboration (clinical training programs, immunization fairs, state and local health departments), technology paves the way.
- Being part of larger discussions on the importance of testing/vaccination, including point-of-care testing.
- Make it easy for providers to implement vaccine and screening services in their practices.

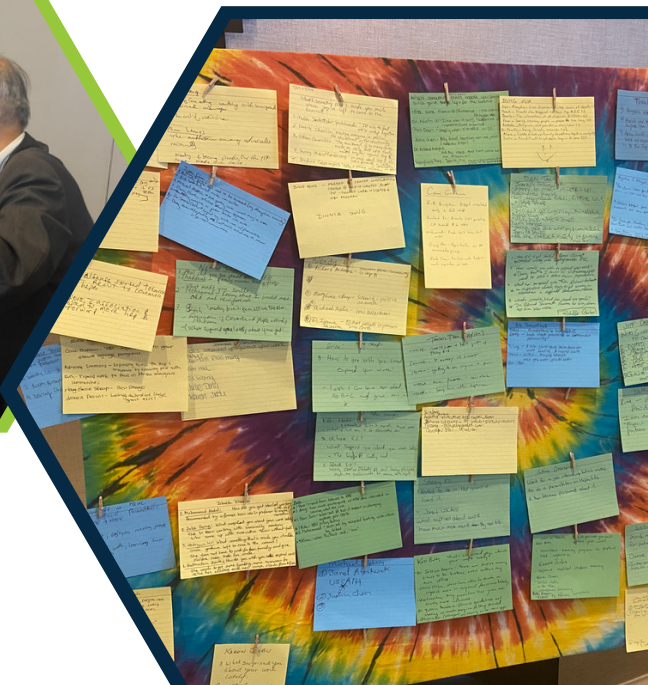


Session 3: Team-Building Exercise - Cousins Connections

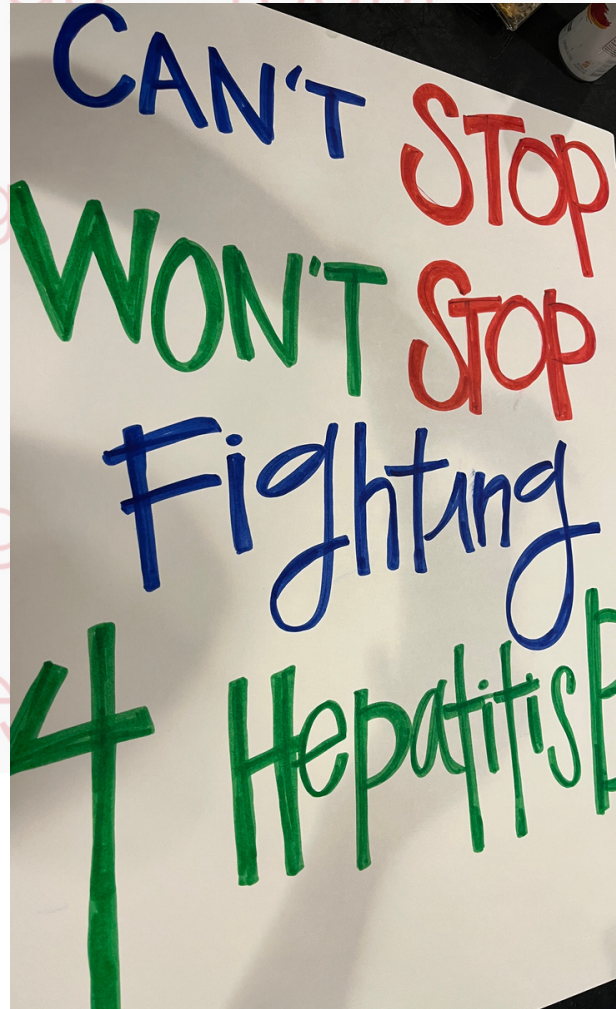
Attendees partnered up and every time the timer went off, they had two minutes to get introduced and to ask and answer a question from the prompts:

- a. How did you get started working in hepatitis B?
- b. How do you wish you could expand your work?
- c. What's surprised you about your work lately?
- d. Something that's made you smile since coming to the Summit?

At the end of the two minutes, attendees would write down their partner's name and something interesting they learned about them. At the end of the activity, we posted them for others to see!



A Family Reunited



Session 4: Hepatitis B Treatment and Management Updates

Hepatitis B Treatment Pipeline



Dr. Timothy Block, founder and past President of the Hepatitis B Foundation gave an update on hepatitis B medication and drug development. Dr. Block discussed the Hepatitis B/ Hepatitis D drug discovery timeline. We have approved antiviral medications, and many compounds in pre-clinical and clinical development. He mentioned the need to keep a focus on hepatitis B, especially as companies might lose interest over time. We need to push for more federal funding as well as push the commercial sector. The good news is that 3-5% of hepatitis B infections are curable with current therapies.

Clinical Trial Updates

Dr. Yasmin Ibrahim, from the Hepatitis B Foundation talked about the current state of clinical trials, participation trends and challenges around recruiting people. Participation in clinical trials comes with many structural and attitudinal barriers. A survey conducted by Hepatitis B Foundation's Patient Engagement Program has shown that over 70% of people were willing to participate in clinical trials. A barrier for people living with hepatitis B is that they often do not have adequate information or knowledge on clinical trials. Dr. Ibrahim discussed the need for new patient-focused clinical trials, to ensure diversity and build capacity of people living with hepatitis B.



Treatment Guideline Updates



Dr. Su Wang, Senior Global Advisor for the Hepatitis B Foundation gave important updates about hepatitis B treatment guidelines which included information on the benefits and risks of expanding treatment. Dr. Wang mentioned that being able to provide treatment to all will help close gaps in treatment, reduce negative outcomes, and help people sustain their care and be more proactive with their health. At the same time, expanding treatment can increase overall healthcare cost and lead to potential viral flares in some people if medication is stopped abruptly. Dr. Wang further mentioned that the aim has to be enhancing quality of life as a goal of hepatitis B therapy, reducing the spread of the virus (reduce population viral load), and reducing health consequences of hepatitis B.



Session 4: Hepatitis B Treatment and Management Updates

Discussion from Session 4

How do we integrate patient preference into medical management and professional guidelines?

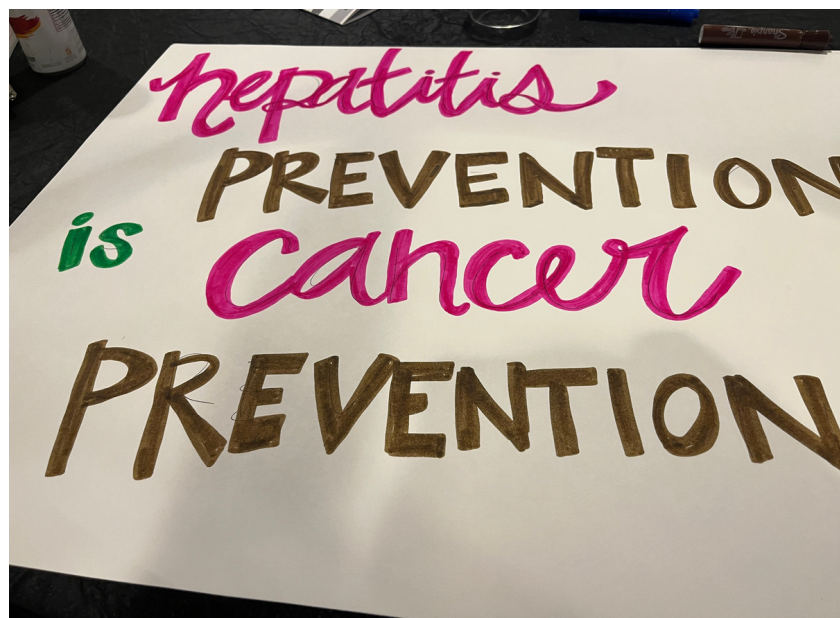
We need to advocate! Some ideas include:

- The community can submit letters/statements to professional medical societies, and ask for meetings and meaningful ways to integrate patient and community preferences.
- Hep B United can consider creating a working group to discuss and implement strategies.

Why don't more primary care providers treat/address hepatitis B?

Primary care providers have many health issues to discuss with patients, and hepatitis B is not always priority. Many primary care providers don't have training on hepatitis B specifically. We can help by promoting simplification of treatment and providing accessible provider education, and fostering health system change. Programs like hepatitis B ECHO can be very helpful in improving the capacity of community providers to manage and treat hepatitis B.

The U.S. is very advanced in policy and treatment but has very complex and complicated guidelines and health system. It is often complicated to get people treatment, especially without adequate health insurance coverage. In the U.S., we can learn from other partners globally who have been able to centralize hepatitis B care and simplify treatment algorithms.



Session 5: Mini Grant Report Out & Panel

Mini-Grant Presentations

Recipients of the Hep B United 2022-2023 Mini-Grants Program talked about their projects during the fifth session of the Summit.

Asian Health Coalition

Asian Health Coalition have held two focus groups within the PWUD community, one with counselors who service the PWUD population and the other with former drug users. Informed by these focus groups, Asian Health Coalition have decided to divide their outreach efforts into three categories so that they can best reach active, recovering, and former users. They plan to reach active users through stickers and business cards. The stickers and business cards will have QR codes that will lead to websites and resources to obtain more information on hepatitis B.

Center for Asian Health - Cooperman Barnabas Medical Center

New Jersey is the fourth largest state with AAPI population. They have a culturally sensitive medical care with bilingual providers, community-based outreach and screening. So far 144,000 individuals have been screened and their rate of linking patients to care is 83%. They have established relationships with community partners – dept of health, faith-based groups, community groups which helps them with outreach as well as marketing and media relations.

African Health Coalition

African Immigrant Communities are one of the most hepatitis B impacted communities and also one of the least represented communities. African Health Coalition has been highlighting education, linkage to care and providing community outreach services. The mini grant has been helpful to provide hep B screening to community members. They have also been working on their capacity building services and training community health workers with the aim of strengthening their reach to the community.



Session 5: Mini Grant Report Out & Panel

Mini Grantees Presentations

Community Welfare Services of Metro Detroit

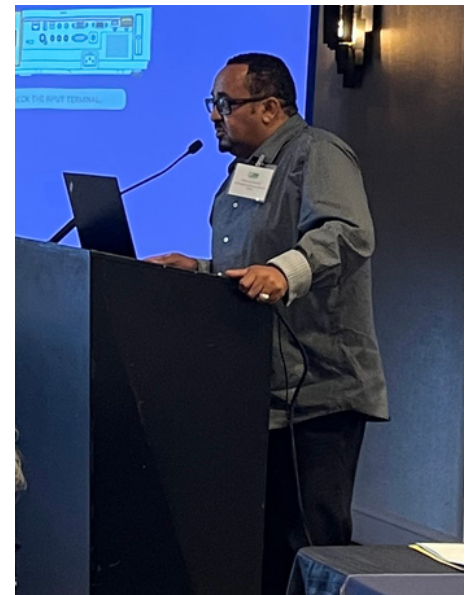
Community Welfare Services of Metro Detroit mainly serves Bangladeshi population in the Detroit area. This community lacks awareness about hepatitis B. Community Welfare Services have been working on providing hepatitis B information and awareness to this community. They feel that framing educational messages as liver cancer prevention is crucial and will help convey the urgency of screening and vaccination. They have started an awareness program with the help of religious leaders and they have also been reaching out to local physicians to spread the word about hepatitis B.

Vital Access Care Foundation (VACF)

Cancer is the top cause of mortality in the Vietnamese Community. Orange County in California has the highest Vietnamese population outside of Vietnam. Vital Access Care Foundation has been working to spread awareness, increase screening and link patients to care in this community. They partner with local hospitals and providers for large-scale education and screening events, all in one place, this gets people close together. They also use social media, radio, faith-based settings, organized workshops for community members, as well as screenings; provide in-language interpretation of test results; navigation and referral to appropriate services.

Hep B Coalition of Washington

Hep B Coalition of Washington mainly works with Afghan and Ethiopian/Eritrean communities. Both these communities have been affected by war and conflict. They have been using storytelling and media services to increase education and awareness about hep B in these communities.



Session 6: #justB Storytelling Panel

Advocating for Change

Four #justB storytellers presented their stories and advocated for increasing awareness, decreasing stigma and discrimination, and promoting testing, vaccination, linkage to care and life-saving treatment.

Richelle

Richelle grew up struggling with stomach problems that went undiagnosed. When she was 18, she learned she has hepatitis B after trying to donate to a military blood drive. Richelle faced isolation, stigma, and discrimination in her personal and professional life, including when the military moved her from the medical field to a supply career. More than three decades later, Richelle is back in the medical field, and all of her kids were successfully vaccinated against hepatitis B at birth.



Adama

After suspecting something was wrong for a while, Adama's mother passed away without a diagnosis or treatment. It wasn't until 10 years later, when Adama tested positive for hepatitis B and experienced the same symptoms, that he realized his mom had suffered from the same virus. Adama is now managing his hepatitis B and receiving treatment, but is concerned about the low awareness of hepatitis B in his community.



Jacki

When Jacki learned that his brother's liver cancer was caused by hepatitis B, he got tested and found out he had the virus, too. Later, his wife also found out she has hepatitis B. When she got pregnant, they did their research and were able to prevent mother-to-child transmission. Jacki and his wife are taking medication to manage their hepatitis B and have started a Taiwanese hepatitis B patient group. Today, all of their kids are hepatitis-free, and Jacki's brother is cured of liver cancer!



Wendy

Wendy faced a lot of stigma when she first found out about her hepatitis B diagnosis. She felt as if she has been isolated and looked at in a different way. The lack of awareness about hepatitis B also did not help. As a new patient advocate, she participates in local, national, and global initiatives to support the elimination of hepatitis B. She is a health seeker who incorporates healthy eating, intentional lifestyle choices, and attention to wellness as a way to manage living with Hep B.



Session 7: Communicating Hepatitis B in a Changing Landscape

Hawai'i Hepatitis B Mortality Report & Hepatitis B Data from Electronic Medical Records

Thaddeus Pham from Hep Free Hawai'i and Josh Mishkin from Kalihi-Palama Health Center discussed some of the data collection strategies they have adopted, talked about hepatitis B data opportunities and highlighted how data can be used in the hep B space. Highlights from this session are below:

Highlight Findings:

- Hawai'i hepatitis B mortality rate has consistently been higher than the national average for the past 20 years.
- Hawai'i has one of the highest hepatitis B-associated mortality rates of any state nationwide. In 2019, the rate for Hawai'i was almost 3-times the national rate.
- API residents of Hawaii have had disproportionately high hepatitis B-related death rates for the past 20 years.

Hep Free Hawai'i were able to leverage this data and publish a report educating the community and partners about the high incidence and mortality due to hepatitis B and liver cancer. They shared the data on the health department website, HepFreeHawaii website, issued a press release, issued media reports, and conducted radio interviews. This has been used for both education, awareness and advocacy, and has been a useful tool and resource for promoting positive change.

How they Turned Data to Action

- Use the data you have access too
- simplify your data so that different stakeholders can understand what the data mean
- Publish in local journals, cite the data in educational materials
- create simple, 1-page handouts
- Use visuals and condense information into the most important findings/message
- Use social media--infographics, TikTok

Discussion

How can we use data for private stakeholders, for fundraising? Focus on social math: show the impact of something without using numbers. This is an opportunity to get attention, and highlight the strong points to see if it generates more discussion. Data makes stakeholders ask more questions! You need to understand the goals and use your data appropriately. Are you seeking funding? Improving awareness? You want to focus your data and your message depending on the audience.



Session 8: Communicating More Effectively

Harnessing Social Media

In this session, *Edward Tate, Director of Communications and Marketing at the Hepatitis B Foundation* gave useful information on how social media can be used in an effective and way to make work more fruitful and have it reach more people.

Even small organizations can make their work more impactful by presence on social media. Use of hashtags (with moderation), photos of people's faces, providing high value content and not just promotional materials, timeliness can help with increasing reach with social media. Small organizations can leverage students! There are many creative, productive and tech savvy interns to help create materials to post and organize social media. Having a social media calendar, using design tools such as Canva and scheduling posts beforehand with Hootsuite might also be some useful ways of using social media effectively. At the same time it is also useful to promote inclusivity, create culturally sensitive materials and always have an extra pair of eyes to review campaign materials.



Session 9: State of Hep B United

Updates on New and Existing Programs

Mini Grants

- RFP went out early June
- Application deadline was August 3
- Applications reviewed by a group of external and internal reviewers
- Acceptation notice early September
- New cycle starts September 30

Peer Mentorship

- Reoccurring annual program
- Eleven pairs across eight cohort since 2014
- Nine-month long funding
- New Cohort started May 1

Webinars

- Approx 50 mins long
- Every other month
- Topics picked from community survey or need
- Recordings posted and promoted
- Heavy viewership

B informed! A Hepatitis B Virtual Education Series

- New program, launched May 16
- Approx 45 minutes long
- Replicates Echo model
- Short didactic presentation and a case study
- Improve knowledge and capacity of professionals and public health community

Community Health Center Learning Collaborative

- New program
- To help community clinics integrate best practices for hepatitis B screening, vaccination
- Small cohorts of 2-4 community based health centers
- Four one and half hour sessions in a row and complete assignments
- A learning collaborative program for the NH/PI community is being developed



Session 9: State of Hep B United

Updates on Work Groups

Health Equity Workgroup (led by Chioma Nnaji)

- Currently building a health equity toolkit that will be used to assess equity of HBU's capacity building programs.

Native Hawaiian/ Pacific Islander Workgroup (led by Dr. Nia Aitaioto)

- Have completed community leader and community member focus groups and are now compiling the data into a report to be used to guide NH/PI-focused outreach and materials.

Harm Reduction Workgroup (led and presented by Dr. Amy Jessop)

- Semi structured interviews were conducted to figure out what's happening in harm reduction setting in regards to hepatitis B.
- Recruited leaders within U.S. based harm reduction organizations.
- Interviewed 20 individuals between December 2022 and February 2023.
- Results showed that most did not conduct hepatitis B specific activities, those who do have limited services, have low level of knowledge and awareness and have lower prioritization.
- Public health approached is needed to address hepatitis B in communities of PWID
- Harm reduction organizations need support to meet needs.



Summit Activities

Family Tree

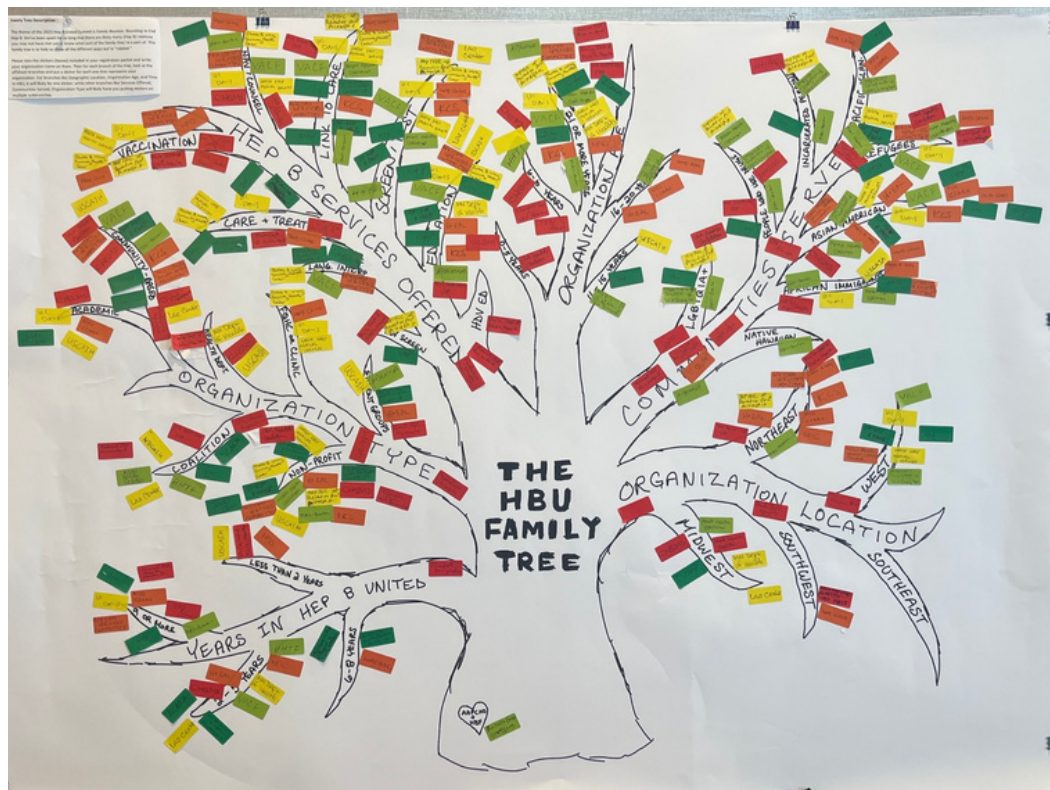
The theme of the 2023 Hep B United Summit was *Family Reunion: Reuniting to End Hep B*. We had been apart for so long that there were many (Hep B) relatives we had not met yet or know what part of the family they're a part of. This family tree exercise was created to help us show all the different ways we're "related."

Attendees took the stickers (leaves) included in their registration packet and wrote their organization name on them. Then for each branch of the tree's shoot branches, they put a sticker for each one that represents their organization. For branches like Geographic Location, Organization Age, and Time in HBU, they added one sticker; while other branches like Services Offered, Communities Served, and Organization Type had participants putting stickers on multiple subbranches.

Cafe Corkboard

This idea was inspired by the corkboard at local cafés. The one plastered with flyers from folks offering lawn mowing or asking for nanny services or musicians plugging their next gig? This activity was the Family Reunion's version of one of those.

Attendees were asked to grab a flier from the materials available and wrote out the help they wanted, or the help they're offering. They were also asked to include their name on the tags so folks could reach out! And if they doodles something during the sessions, then they were asked to pin it in the Doodle Corner and share with others.



Advocacy Day and World Hepatitis Day

Advocacy Day

Our Advocacy Day took place one day after the Summit on July 26th. Over 50 partners helped HBU bring the needs of the hepatitis B community to the attention of Members of Congress. Frank Hood, MPA, Director of HBU, Rhea Racho, HBF's Public Policy and Program Manager, Michaela Jackson, Program Director Prevention Policy and Adam Carbullido from the Association of Asian Pacific Community Health Organizations (AAPCHO), led preparation for the meetings on Capitol Hill.

More than 40 offices were visited. During meetings with their representatives, advocates asked for support for: 1) increased funding for CDC's viral hepatitis programs and 2) include hepatitis B in national hepatitis C elimination plan.



World Hepatitis Day

Each year, World Hepatitis Day is observed on July 28th. This day was chosen because it was Dr. Baruch Blumberg's birthday. Dr. Blumberg identified the hepatitis B virus and helped develop tests and vaccines for the disease. This year HBU celebrated Dr. Blumberg's birthday with partners, staff, and guests from all over the United States.



Final Thoughts



Conclusion

Hep B United's eighth annual summit showcased what can be achieved if legislators, government organizations, community groups, and advocates all come together. Having many of the major players in the national hepatitis community in one room not only provides a platform to voice concerns and challenges, but it opens the floor for progress and growth as a cohesive unit. By the end of the summit, coalition members were able to walk away with a wealth of new tools and information, as well as a feelings of strength and solidarity from within the hepatitis B community.

Stay Connected

Hep B United has an active online presence. Come join our community!



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