



SUMMIT REPORT



JULY 24 - 26, 2018

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INTRODUCTION AND SUMMIT GOALS

The 6th Annual *Hep B United National Summit* was held in Washington, D.C. on July 24-26, 2018 - just a few days before World Hepatitis Day on July 28th. The 2018 summit theme was *Achieving Health Equity to End Hepatitis B*. Approximately 80 people from 50 organizations, campaigns, and coalitions from around the United States joined Hep B United (HBU) to learn more about the current state of hepatitis B in the health world and to fight for increased support and prioritization from the federal government.

The Summit provides federal, state, and community-based organizations with the opportunity to join forces and share their expertise and knowledge. The collaborative work that is done at the Summit provides momentum for the hepatitis B community

and allows for the growth of new ideas and plans of action on both a community and organizational level. Each annual Summit advances our movement to effectively address hepatitis B, reflect on recent successes, and move the community one step closer to eliminating hepatitis B. The overall objective for the Summit is to work towards the goals of Hep B United.

OUR GOALS

- **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 Asian Americans, Pacific Islanders and other high-risk communities.
- **Intervention:** Improve access to care and treatment for individuals living with hepatitis B to prevent end-stage liver disease and liver cancer.

THE STATE OF HEP B UNITED

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. With partners in 26 cities, 19 states, and the District of Columbia, Hep B United has a reach of over 6 million Asian Americans and Pacific Islanders. Since the coalition was established, community partners have conducted over 72, 659 educational sessions, screened over 28,000 high-risk individuals, and participated in dozens of media and advocacy events regionally and nationally. A major contributor to Hep B United's continued success is the *Know Hepatitis B Campaign*, a national, multi-lingual Centers for Disease Control and Prevention (CDC) communications campaign to improve awareness and knowledge about hepatitis B and promote hepatitis B screening.

The campaign, led by *Dr. Cynthia Jorgensen, Team Lead for Communication, Education and Training at the CDC Division of Viral Hepatitis (DVH)*, is co-branded with Hep B United. It provides diverse tools and multi-platform resources for local coalitions, and represents a successful ongoing partnership between Hep B United and the CDC.

Since the 2017 Summit, Hep B United has released a fact sheet on hepatitis B and the opioid epidemic, welcomed new community partners to the coalition, and presented six more mini-grants to coalition partners across the country. Hep B United also partnered with a variety of organizations - including the National Viral Hepatitis Roundtable (NVHR), the World Hepatitis Alliance (WHA) and the #NOhep campaign, AAPCHO, and the George Washington University Cancer Center - to bring a diverse array of educational webinars to the hepatitis B community.



THE JOURNEY TO HEALTH EQUITY

*Dr. Tamara Henry from the George Washington University Milken Institute School of Public Health kicked off the summit with a keynote presentation on our theme, *Applying a Health Equity Lens to Eliminating Hepatitis B*. During this session, she provided perspectives on hepatitis B-related health disparities, racism within the public health field, and how equity differs from equality. Dr. Henry also provided solutions to some of the typical barriers to health equity, such as being self-aware of words used while addressing groups that face health disparities and using Community-Based Participatory Research.*

HEP B UNITED: A YEAR IN REVIEW

Kate Moraras, HBF's senior program director and the director of Hep B United, shared Hep B United's growth and accomplishments over the past year. Hep B United's capacity building program, which provides training and technical assistance through webinars, reached nearly 2,000 viewers in 2017. Through Hep B United's mini-grants, which aim to increase innovative community-based hepatitis B education, testing, and linkage to care initiatives, grantees educated over 13,000 individuals about hepatitis B and screened over 7,500 individuals for hepatitis B infection. Hep B United also welcomed three new partners, including hepatitis B coalitions in Colorado and Michigan and Team HBV. Hep B United is now combating hepatitis B in 19 states and the District of Columbia!

DEVELOPING A NEW VALUES STATEMENT

Jacqueline Coleman from Vision Que! led Hep B United partners in a session that reflected on the coalition's principles and a new draft of Hep B United's values statement. Hep B United members approved and provided comments on the draft. Suggestions included emphasizing the coalition's evidence-based efforts and condensing the information to make the overall message more powerful and concise. The finalized statement will be announced in Fall 2018.



“CIVIL RIGHTS PROTECTIONS & NON-DISCRIMINATORY STANDARDS NEED TO BE AT THE FEDERAL LEVEL.”

- WAYNE TURNER, NATIONAL HEALTH LAW PROGRAM (NHELP)



KNOW HEPATITIS B CAMPAIGN UPDATES

Dr. Cynthia Jorgensen and Sherry Chen from the Division of Viral Hepatitis at the CDC provided an overview of the Know Hepatitis B Campaign, which includes resources in a variety of languages. At the summit, they shared a new, customizable infographic promoting the hepatitis B vaccine for newborns. The Know Hepatitis B Campaign ads are distributed to both social and traditional media outlets. Since its launch, the campaign has resulted in 461 million impressions and a media value of about \$3.7 million.

AFRICAN IMMIGRANT PROJECT

Sierra Pellechio from the Hepatitis B Foundation shared results from a needs-based assessment project focused on strategies for improving screening, increasing hepatitis B awareness, and linkage to care in African Immigrant communities.

VACCINATE YOUR BABY AGAINST HEPATITIS B
IT COULD SAVE YOUR BABY'S LIFE.

WHAT IS HEPATITIS B?

- HEPATITIS B** is a serious liver disease caused by the **HEPATITIS B VIRUS**.
- HEPATITIS B OFTEN DOESN'T CAUSE SYMPTOMS.** Many people can live with hepatitis B for years without feeling sick.
- 1 IN 4 people living with hepatitis B can develop serious liver problems, INCLUDING LIVER CANCER.**

DID YOU KNOW?

- All pregnant women are routinely tested for hepatitis B.
- People who find out they have hepatitis B can take steps to keep their baby and family protected.
- The **HEPATITIS B VACCINE** is the 1st cancer prevention vaccine.



Findings from phase 1 of the project included learning about low levels of hepatitis B awareness, cultural and religious beliefs, stigma, and common barriers to accessing health care. In phase 2, which is currently underway, the team is developing educational materials to help individuals become hepatitis B leaders in their community. The presentation was followed by a question and answer session with the audience.

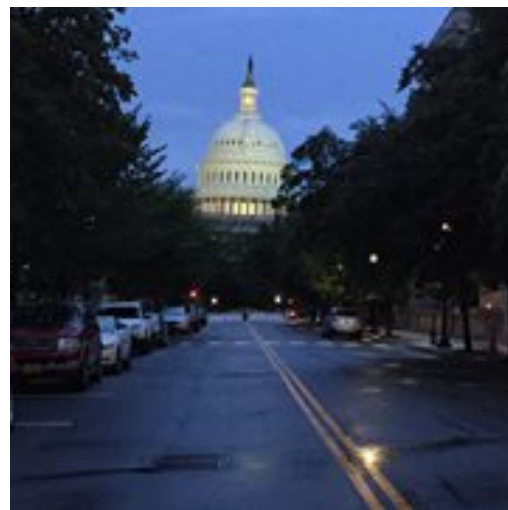
Q&A WITH FEDERAL PARTNERS

Corrina Dan from the Department of Health and Human Services (HHS), Dr. Judith Steinberg from the Health Resources & Services Administration, and Dr. David Wong from HHS Office of Minority Health joined Dr. Paul Weidle, Dr. Sarah Schillie, and Nancy Fenlon from the CDC for the Federal-Community Partnership to Eliminate Hepatitis B session.

The group shared updates and perspectives on federal-community activities to achieve Hep B United's Strategic Priorities. During a brief update, they noted that 11,500 pregnant women are identified per year through surveillance and that approximately 96% of infants born to mothers with hepatitis B receive the HBIG shot and first vaccine dose within 24 hours. Panel topics included updates to the National Viral Hepatitis Action Plan, strategies to increase adult hepatitis B vaccination coverage, improving hepatitis B surveillance, testing and treatment within the primary care system, and preventing mother to child hepatitis B transmission.

PREVENTING PERINATAL TRANSMISSION

Dr. Amy Tang facilitated a session on preventing perinatal hepatitis B transmission featuring three panelists: Ruth Brogden from the Center for Asian Health at Saint Barnabas Medical Center in New Jersey, Janice Lyu from the Charles B. Wang Community Health Center and Liz Tang from the New York City Department of Health and Mental Hygiene. The discussion was centered on interventions to optimize the birth dose, a primary care model for management of hepatitis B during pregnancy, and strategies to increase maternal engagement in hepatitis B medical care after delivery.



COMBATING STIGMA AND DISCRIMINATION

Nadine Shiroma from HBF and Rita Kuwahara from AAPCHO led a presentation on combating hepatitis B-related stigma and discrimination. The session clarified the definitions of stigma and institutional discrimination, provided an overview of the AAPCHO Hepatitis B and Stigma Toolkit, and identified specific cases of hepatitis B-related institutional discrimination with examples from medical and dental schools and the military. The audience was also reminded that legislation like the Civil Rights Act and the Americans with Disabilities Act protects those with hepatitis B from discrimination. AAPCHO's comprehensive toolkit, which can be found [online](#), presents solutions to stigma at both individual and system levels.

EXPANDING HEPATITIS B SCREENING TO MORE HIGH RISK COMMUNITIES

The breakout session on expanding hepatitis B screening to other high-risk communities featured Hep B United partners *Arman Altug* from the *Hepatitis Education Project*, *Thaddeus Pham* from *Hep Free Hawaii*, and *Jack Hildick-Smith* from the *Philadelphia Department of Public Health*. Panelists discussed outreach strategies targeting LGBTQ communities, incarcerated individuals, and people who inject drugs or who use harm reduction services. Treating incarcerated individuals with respect, being conscious of a person's preferred name and/or gender identity, and examining areas of missed outreach opportunities for high risk communities were among the main takeaways from the session.



HEP B UNITED MINI-GRANT REVIEW

Developing Innovative Practices in Hepatitis B Education and Screening featured four grantees from the 2017 Hep B United mini-grant and peer mentoring programs. *Xuan Phan* from *Mercy Housing and Human Development in Gulfport, Mississippi*, shared results from working with her peer mentor, *Dan Tam Phan-Hoang* from *HBI-Minnesota*, who provided expertise and experience in working with a similar target population. Presenters from the 2017-2018 Hep B United's mini-grant program included *Loyal Rabat* from *Asian Pacific Community in Action in Phoenix, AZ*, *Karen Jiobu* from *Asian American Community Services in Columbus, OH*, and *Brandi Dobbs* from *Asian Services in Action in Cleveland, OH*. The grantees shared the innovative strategies they implemented to increase hepatitis B education and screening in their communities.



IMPROVING ACCESS TO HEPATITIS B TREATMENT

The session focused on discrimination in hepatitis B medication pricing and access to treatment. *Sierra Pellechio and Lauren Su from the Hepatitis B Foundation* provided an overview of current hepatitis B medication tiering practices by insurance companies. *Wayne Turner from the National Health Law Program (NHeLP)* defined legal language that presented barriers to health equity and identified tactics that insurance companies typically use to deny individuals fair coverage. When speaking about Section 1557 of the Affordable Care Act - the non-discriminatory clause - Turner said, "It shouldn't be about where you live...[to determine] what access you have to healthcare."

INCREASING PROVIDER KNOWLEDGE

Dr. Richard Andrews from HOPE clinic and Co-Chair of the National Task Force on Hepatitis B moderated a session discussing the results of the Task Force's provider education program being implemented across the country. Six panelists shared their experiences convening regional continuing hepatitis B education sessions: *Catherine Freeland from HBF, Dr. Amy Tang from the Charles B. Wang Community Health Center, Mohammed Abdul-Kadir from the International Community Health Services and the Hep B Coalition of Washington State, Binh*

Tran from the Asian Pacific Health Foundation, Xuan Phan from Mercy Housing and Human Development, Lu-Yu Hwang from the University of Texas Health's School of Public Health, and Dan Tam Phan-Hoang from HBI-Minnesota. The panelists noted that in-person trainings were more effective than webinars and other internet-based learning methods. In-person meetings allowed for more engagement from the trainees. In addition, the training sessions included networking opportunities, which helped to connect providers to hepatitis B resources in their communities. Education sessions took place at seven different locations across the country, including Philadelphia, Pennsylvania, Biloxi, Mississippi, and Kahului, Hawaii.

WORLD HEPATITIS DAY

Hep B United helped to commemorate World Hepatitis Day on July 28th by asking the question, "Why should people get tested for hepatitis B?" The question was developed in response to this year's theme - Find the Missing Millions. Responses poured in from all over the world and were compiled into a video that can be found on the [Hepatitis B Foundation's YouTube channel](#). The theme was meant to bring attention to the 90% of infected individuals that don't know that they have it. On social media, the hashtag #FindtheMissingMillions was used to raise awareness.





ADVOCACY DAY

Each year before the official start of the Summit, attendees are invited to participate in a hepatitis B advocacy day on Capitol Hill. More than 65 participants were able to meet with 61 Congressional offices in just under four hours! During the advocacy training, *Rachna Choudhry*, co-founder and Chief Marketing Office of POPVOX, spoke to attendees about how to best utilize their time on the Hill. Advocates asked their representatives to support 1) more funding for the CDC's Division of Viral Hepatitis for expanded surveillance and prevention programs, 2) increased funding for the National Institutes of Health (NIH) in order to support research towards providing a cure for hepatitis B and improving treatment options, and 3) for the protection of laws and increased resources that provide access to the hepatitis B vaccine in order to increase vaccination rates among adults. On Wednesday, July 25, *Senator Mazie Hirono* from Hawaii, and Representatives *Judy Chu* from California's 27th district, *Hank Johnson* from Georgia's 4th district, and *Brian Fitzpatrick* from Pennsylvania's 8th district joined a Congressional reception hosted by the Hepatitis B Foundation to recognize community and Congressional Hep B Champions.



HEP B CHAMPIONS 2018

In addition to providing a time to network during the Summit, the Congressional reception is also a time to recognize some of our partners for their dedication and hard work.

Senator Hirono, who represents Hawaii, received the first annual Hepatitis B Congressional Champions Award for her continuous efforts to make hepatitis B a federal priority.

Arman Altug, the Hep B Program Manager and Outreach Specialist at the Hepatitis Education Project (HEP), was acknowledged for his outreach in medically underserved communities in Seattle. Arman has focused his work on raising awareness and providing education on hepatitis in the Washington state prison population.

The *Charles B. Wang Community Health Center* in New York was recognized for their dedication and excellence in hepatitis B care and prevention. The center's "Hep B Moms" program, which focuses on preventing and eliminating perinatal transmission of hep B, serves as an example to other health centers.

Kenson and Rensely Alik from HBF's #justB storytelling campaign and *Hep Free Hawaii* were also recognized at the reception. Since Kenson's chronic hepatitis B diagnosis, the couple has been committed to paving the way for hepatitis B advocacy and awareness in Hawaii.



#JUSTB STORYTELLER REUNION

The #justB reunion took place on July 23, 2018. Twelve storytellers from our 2017 and 2018 digital storytelling workshops reunited in Washington, DC for a follow-up training to reflect on their involvement in the [#justB campaign](#), discuss ways to maintain and increase storyteller engagement, and to share ideas and feedback on how to continue building and improving the storytelling program. Storytellers had the opportunity to catch up with the other participants, engage with the new #justB participants, and strategize about how to continue supporting one another and work together to raise awareness and reduce stigma around hepatitis B.

Storytellers also participated in the advocacy day on Capitol Hill. A few of the storytellers also participated in the Hep B United Summit, including Nancy Pyon of Ohio and her daughter - an "advocate in training", who shared their stories during the Hepatitis B Community Reception on the Hill.

CONCLUSION

The sixth annual *Hep B United National Summit* was the largest one yet! Participants visited 23 more Congressional offices than in 2017 and summit attendance increased by 60%. Coalition members were thrilled to network with individuals from across the country, meet federal partners, share best practices and experiences, and reflect upon the future of Hep B United. On the final day of the Summit, members discussed next steps and how to utilize the new information they received. With new goals and a fresh outlook on the state of hepatitis B, Hep B United is ready to tackle the remainder of the year and continue the fight to eliminate hepatitis B!

STAY CONNECTED

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



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