



# SUMMIT REPORT

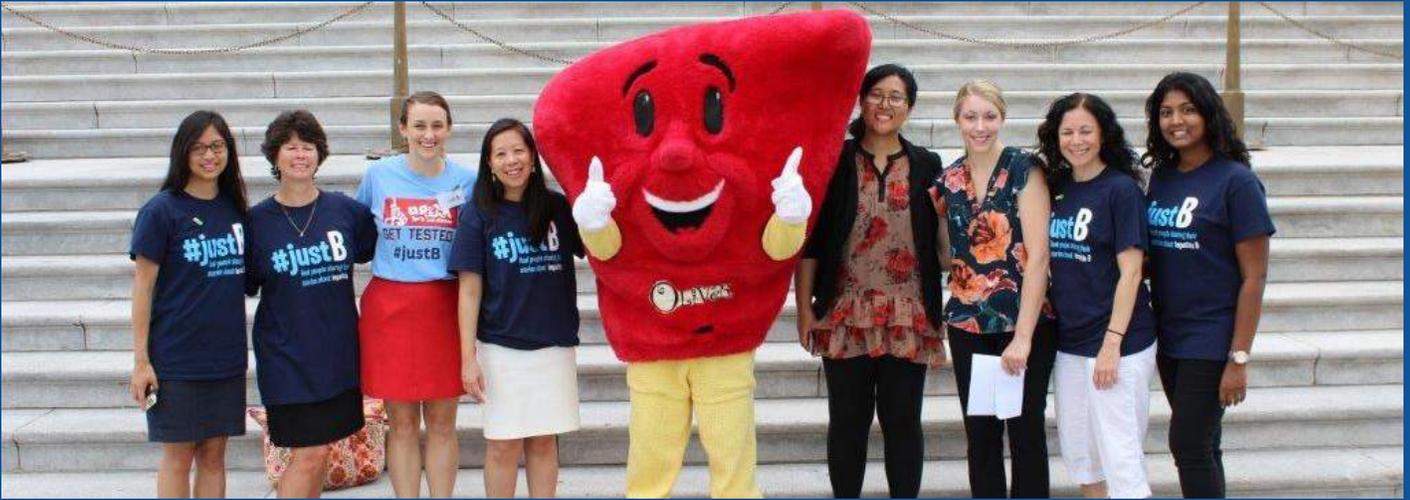


**JULY 26 - 28, 2017**

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## INTRODUCTION AND SUMMIT GOALS

The 5th Annual *Hep B United National Summit* was held in Washington, D.C. July 26-28, 2017, coinciding with World Hepatitis Day on July 28th. Over 80 individuals from over 40 partner organizations attended. The *Hep B United National Summit* is the largest convening of hepatitis B leaders from community coalitions, national nonprofit organizations, individuals and family members affected by hepatitis B, federal partners, and public health agencies across the United States. The Summit serves as a coalition-strengthening opportunity for partners to engage at multiple levels to share experiences and best practices for hepatitis B education, screening, research, linkage to care, and outreach. In addition, the Summit fosters collaboration and networking among coalition partners.

Each annual Summit advances our movement to address hepatitis B, reflect on recent successes, and plan for the future. The overall objective for the Summit is to work towards the goals of Hep B United which were highlighted in the [HBU report](#).

## 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 U.S. With partners in 27 cities and 22 states and the District of Columbia, HBU has a reach of over 6 million Asian Americans and Pacific Islanders. Since HBU was established, community partners conducted over 52,194 educational sessions, screened over 22,500 high-risk individuals, and participate in dozens of media and advocacy events regionally and nationally. A major contributor to this 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 HBV and promote HBV

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

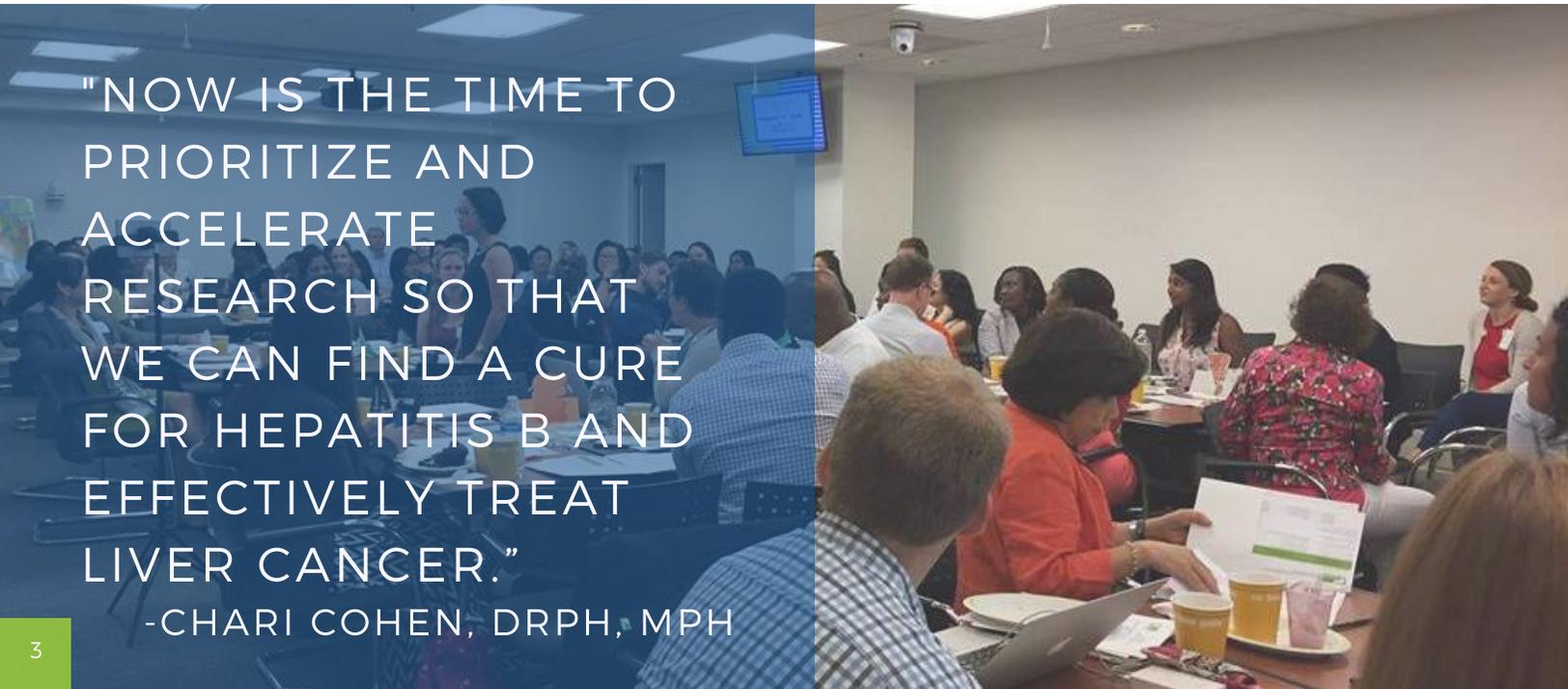
*Dr. Tim Block, President and Co-Founder of the Hepatitis B Foundation, Dr. Chari Cohen the new Co-Chair of HBU and HBF Director of Public Health, and Isha Weerasinghe, AAPCHO Director of Policy and Advocacy, welcomed summit attendees. Dr. Block noted the positive impact HBU has on those affected by hepatitis B nationally, and provided an update on the Hepatitis B Foundation Hep B Cure Campaign which calls for increased federal*

investment to accelerate the pace of research for a cure. Dr. Cohen thanked the newly retired Joan Block, the past Co-Chair of HBU, Co-Founder and former Executive Director of the Hepatitis B Foundation for her continued dedication to advocacy and public health efforts for hepatitis B patients worldwide. In Dr. Cohen's opening remarks she stated, "Working together, we can eliminate hepatitis B in the U.S., but it will mean prioritizing hepatitis B as an urgent public health problem. Now is the time to prioritize and accelerate research so that we can find a cure for hepatitis B and effectively treat liver cancer." Isha Weerasinghe provided a welcome from AAPCHO and congratulated coalition leaders for their dedication and hard work for the past five years. This document provides an overview highlighting sessions throughout the 2017 HBU Summit.

## TIME TO ELIMINATE HEPATITIS B

Dr. John Ward, Director of CDC's Division of Viral Hepatitis, provided an overview of hepatitis B in the United States and discussed pathways and strategies to meet the World Health Organization (WHO) goal of hepatitis elimination by 2030. Dr. Ward noted the increase in HBV cases by 21% in 12 states associated with the opioid epidemic in addition to the lack of surveillance on acute HBV cases, with only 10 states requiring reporting. Dr. Ward also provided an opportunity for Summit participants to ask questions and share their concerns.

Several participants shared their concerns that the siloed nature of the perinatal hepatitis B prevention coordinators and adult viral hepatitis programs within health departments causes challenges and



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-CHARI COHEN, DRPH, MPH

duplicates efforts in a climate of shrinking resources. Additionally, the lack of surveillance data in the U.S. was mentioned as a priority issue for coalition participants. Participants also mentioned the lack of funding for HBV prevention programs was a concern that demonstrates a lack of prioritization at the federal level for elimination of hepatitis B.

## #JUSTB STORYTELLING CAMPAIGN OVERVIEW AND PANEL

Rhea Racho, Public Health Policy and Program Coordinator at the Hepatitis B Foundation provided an overview of the [#justB Campaign](#). The [#justB Storytelling Campaign](#) was launched officially in May 2017 with the goal of increasing awareness, advocacy, decreasing stigma, promoting testing, and encouraging linkage to care for hepatitis B on a national scale. The Hepatitis B Foundation partnered with StoryCenter, a non-profit with extensive social justice experience dedicated to sharing stories to raise awareness on key issues. Through intensive workshops, 15 dynamic individuals with a personal connection to hepatitis B created digital stories expressing how hepatitis B has impacted their lives. These digital stories are being broadly disseminated and used to promote discussion and decrease stigma around hepatitis B. This session introduced the [#justB Campaign](#), screened two digital stories, and included a panel discussion of five storytellers.

## #JUSTB PANEL DISCUSSION

Rhea Racho moderated the [#justB](#) panel session which provided insight into the digital



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-#JUSTB STORYTELLER



storytelling process. The first question posed to the panel of storytellers was, “What do you hope people will take away from the #justB stories?” The first respondent said, “I hope people can identify with the issues and understand... that hepatitis B is not a death sentence.” Another storyteller shared, “hepatitis B is a journey, it is very emotional listening to stories, each one unique, we deal with stigma and discrimination even in our own families.” Another storyteller expressed having fears associated with sharing their story, but also noted that sharing can “bring about change because it is a powerful tool.” A storyteller diagnosed with hepatitis B at a young age shared, “living with hepatitis B has been hard, but it makes me stronger, I hope those that see my story can understand my internal struggle

as a new international student in the US.” One storyteller also said, “it took a lot to talk about this, many Africans are afraid to talk about it, not only because of stigma, but also due to a lack of trust. Many Africans are not sure health care providers really want to help them, they are afraid of losing their jobs, and becoming a statistic.” She hopes that Africans can be represented.

Overall, storytellers expressed the desire to increase awareness through their stories so that others are not afraid to get tested for hepatitis B and so people are not ashamed of a hepatitis B diagnosis. Storytellers expressed the need for increased knowledge in the community to work towards reducing the stigma



associated with hepatitis B. The #justB panel encouraged coalition leaders to incorporate storytelling and the #justB Campaign within a local setting through the discussion guide resource and videos.

### INCREASING COMMUNITY AWARENESS AND EDUCATION

*Catherine Freeland, HBF Public Health Program Manager, and Sherry Chen, CDC Health Scientist* presented on experiences working towards increasing community awareness and education utilizing Know Hepatitis B campaign materials and coalition resources. This session provided an overview of most relevant and useful resources, and provided insights on creative ways to integrate Know Hepatitis B resources into coalition activities. Highlights included incorporating the community health

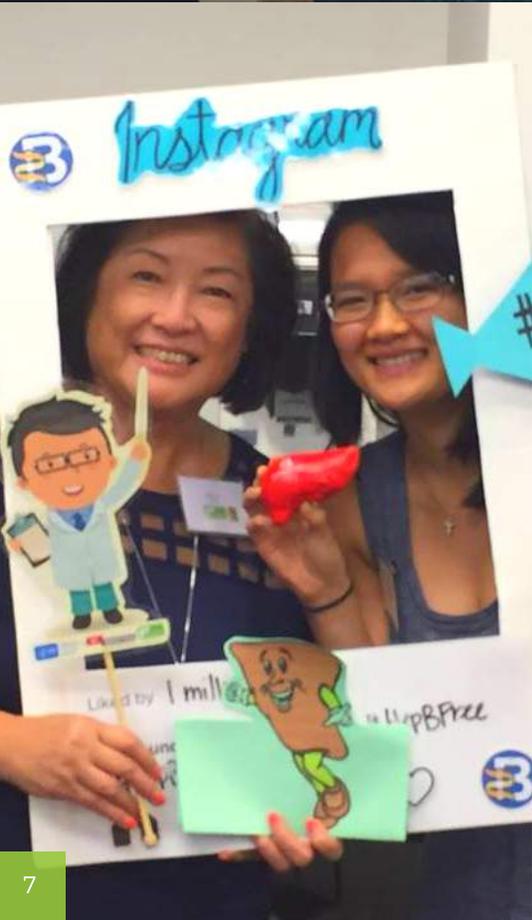
events such as lunch and learns and hepatitis B education sessions. Coalition members were encouraged to evaluate their experiences of the #justB videos included in the Storytelling Discussion Guide. Also in this session, the 2017-2018 Community Education Needs Assessment project was introduced - this project will collect feedback from coalition members regarding existing resource and education needs at the local level. Needs assessment interviews of coalition leaders will take place in late 2017 and results will be presented to coalition partners in 2018.



### PUBLIC HEALTH AND DATA

*Chari Cohen and Thaddeus Pham, Viral Hepatitis Prevention Coordinator for Hawaii* emphasized the importance of data collection for increased





surveillance across the country for hepatitis B. Data is a useful tool when applied to advocacy efforts, building partnerships and grant writing. This session focused on familiarizing partners with resources for finding existing data, how existing data can be used locally in HBV efforts, and how data can be presented to communities and legislators to make it more effective and impactful. A key strategy was looking across population issues to find relevant data, including general population demographics or health insurance data. To further local efforts, the session moderators suggested merging existing data with newly collected HBV-specific data, and using charts, graphs and simple methods for sharing data with local partners.

## GRANT WRITING AND FUNDING OPPORTUNITIES FOR PUBLIC HEALTH

*Chari Cohen and Kathy Ko Chin, President and CEO of the Asian & Pacific Islander American Health Forum (APIAHF) shared their experiences in grant writing and provided valuable insights and steps for the grant writing process. The presentation outlined six steps for developing a grant that included developing an organizational assessment (SWOT analysis) to assess capacity and readiness of an organization to apply for potential funding. Key places to look for potential funding can be through government (state or city health departments, federal agencies), corporations, foundations, and grant-giving non-profits. The priorities that funders often look for in proposals are often linked to experience, infrastructure and sustainability of the applying organization.*

## INCREASING AWARENESS THROUGH MEDIA ENGAGEMENT

Jessie McDonald and Lisa Thong from Weber Shandwick and IW Group presented on the positive impact media engagement can have on public health efforts.

Media has the power to influence thoughts, perceptions, and behavior and can be a useful tool when working in the community setting. This session provided helpful advice for coalition members seeking to increase their media engagement. Key points included word documents, meeting the deadlines of journalists and reaching out to ethnic media outlets: newspaper, radio and web. Reaching ethnic media can be more effective if partners utilize in-language spokespersons as direct resources for messaging.

## HEPATITIS B CME PROVIDER EDUCATION PROGRAM

Amy Trang, Administrator for the National Task Force on Hepatitis B Focus on Asian and Pacific Islander Americans provided an overview of the National Task Force on Hepatitis B and the CME Provider Education Program currently taking place throughout the country. The Health Education for Liver Providers (H.E.L.P.) Training Program focuses on interprofessional education for providers with the overall goal of increasing provider and clinic staff knowledge of the CDC guidelines for hepatitis B and C treatment. This program was developed in



partnership with Dr. Moon Chen, Associate Director for Cancer Control, UC Davis Comprehensive Cancer Center, to improve implementation rates of hepatitis B guidelines nationwide. Currently the program has been piloted in New York, Atlanta, Houston, Seattle, Washington D.C., Chicago and San Diego with hopes to expand throughout the country. Coalition partners interested in hosting a session were encouraged to inquire through Dr. Amy Trang.

mini-grant recipients through a panel discussion. Grantees offered experiences and advice for potential mini grantee applicants and noted their most significant outcomes as a result of the mini-grant projects. The ability to provide follow up care, developing resources for hard to reach populations, building trust and working with new communities directly impacted by hepatitis B were highlighted as positive steps towards achieving the HBU goals.

## HEP B UNITED MINI-GRANT PANEL

The HBU Mini-Grants are offered to coalition partners annually and provide up to \$10,000 for projects that develop new strategies to increase hepatitis B education and screening. The HBU Request for Funding Proposals was released in June 2017, and this session highlighted successes from current

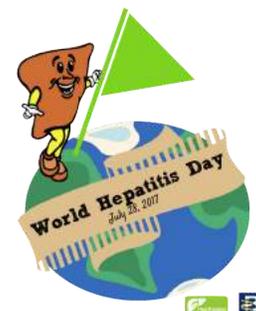
## WORLD HEPATITIS DAY

In recognition of World Hepatitis Day on July 28th, HBU coalition partners participated in a celebratory scavenger hunt on Capitol Hill to increase awareness about the global hepatitis epidemic and a Congressional “meet and greet” photo opportunity with two hepatitis B Congressional





Champions, Congresswoman Judy Chu and Congresswoman Grace Meng. OLIVER™ the Hepatitis B Foundation's liver mascot was also on Capitol Hill to create awareness and celebrate World Hepatitis Day.





## ADVOCACY DAY

Prior to the start of the Summit, over 50 HBU partners participated in an advocacy day on Capitol Hill. Participants met with 38 Congressional representatives from their respective districts to advocate for 1) protection of Medicaid and to oppose efforts to repeal the Affordable Care Act, 2) increase in federal funding for hepatitis B research and programs within the NIH, NCI, and CDC's Division of Viral Hepatitis, 3) a Congressional letter requesting NIH support for a sustained research effort to find a cure for hepatitis B and to 4) recruit Congressional leaders to join the Congressional Hepatitis Caucus. In conjunction with the advocacy day, the Hepatitis B Foundation hosted a Congressional reception for over 80 Congressional staff members and community health advocates.



The reception included an exhibit of personal stories from the #justB storytelling campaign.



## HEP B CHAMPIONS 2017

During the Summit, Hep B United and the CDC presented the *Hep B Champion Award* to five coalition members for their collaborative and successful initiatives to address hepatitis B in their local

communities.

*Vivian Huang, MD, MPH*, the Director of Adult Immunization and Emergency Preparedness for the New York City Department of Health and Mental Hygiene and the medical director for the NYC Department of Health Immunization Clinic is recognized for her commitment to reducing the burden of vaccine-preventable diseases locally and globally including hepatitis B and liver cancer. Dr. Huang

is a strong, tireless advocate for hepatitis B prevention, education, and treatment and health equity through health department engagement.

*Hong Liu, PhD*, the Executive Director of the Midwest Asian Health Association in Chicago, Illinois, is recognized for her innovative approaches to educating the public on hepatitis B and her willingness to share her best practices and experiences with others working in the field.



This year, Dr. Liu's leadership has led her organization to educating over 1,337 individuals in Chicago's Chinatown district and screening close to 300 individuals for hepatitis B.

*The National Task Force on Hepatitis B for AAPI*, is a national organization that brings together scientists, health professionals, non-profit organizations, and concerned citizens in a concerted effort to eliminate the transmission of hepatitis B and to decrease health disparities among those chronically infected. The Task Force is recognized for increasing physicians' awareness about hepatitis B and launching a new health care provider program, bringing together public health and health care professionals in regional meetings around the country. ***The Health Education for Liver Providers (H.E.L.P.) Training Program*** is designed to provide health care providers and their medical team core medical knowledge of hepatitis B and hepatitis C.

*Cathy Phan*, the Health Initiatives Project Manager at HOPE Clinic in Houston, Texas, is recognized for her dedication to reducing health disparities, advocating for access to health care and health equity for underserved populations. Cathy brings unique perspectives, best practices

and creative, innovative ideas from the local community clinics to the national level.

*Dan-Tam Phan-Hoang*, MSc., is program manager of HBI-Minnesota, a Minneapolis, Minnesota-based non-profit that she helped start in 2015. Dan-Tam is recognized for her leadership in Minneapolis, building strong collaborations with community leaders, healthcare providers, funders, and government agencies to address hepatitis B throughout the state and successfully establishing a hepatitis B outreach and prevention program for high-risk communities in the Twin Cities.

## CONCLUSION

Hep B United coalition members greatly enjoyed the opportunity to network with individuals from across the country, meet federal partners, and to share best practices and experiences during the 2017 National Summit. Looking towards the future, coalition members will continue to build upon the learning experiences from the Summit as they go back to their communities working towards our common goal of eliminating hepatitis B in the United States.

