



HEP B UNITED

2019

SUMMIT
REPORT



ELIMINATING HEPATITIS B:
LOCAL CHANGE, GLOBAL
IMPACT



ABOUT HEP B UNITED



Introduction and 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 United States, promoting equitable access to health care, preventive medicine, testing, 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 - Eliminating Hepatitis B: Local Change, Global Impact - highlighted how efforts in one area can have effects that are felt around the world.



We now have 41 partners in 20 states across the country!
Learn more about them at www.hepbunited.org.

Each year, 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 annual 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 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.

LOCAL CHANGE, GLOBAL IMPACT: PARTNERS FROM OCEAN TO OCEAN



New York



Georgia



Arizona



Washington



New Jersey



Mississippi



Colorado



Washington
D.C



Maryland



Pennsylvania



California



Hawaii



Minnesota



Texas

BY THE NUMBERS



Our 7th annual Hep B United Summit was the largest one yet! Held in Washington D.C. from July 23rd-July 25th, the summit brought together a multitude of experts, advocates, and healthcare workers to share their experiences and best practices with one another.

57

**CONGRESSIONAL
OFFICES VISITED
DURING ADVOCACY DAY**

108

**ATTENDEES FROM
OVER 50 ORGANIZATIONS
ACROSS THE NATION**

12

**RESEARCH POSTERS
DISPLAYED AT OUR FIRST
EVER RESEARCH EXHIBIT**



ADVOCACY DAY



Advocacy Day

Our annual advocacy day took place one day before the summit on July 23rd. Over 70 participants helped HBU bring the needs of the hepatitis B community to the attention of Members of Congress. *Kate Moraras, MPH, Director of HBU, Rhea Racho, HBF's Public Policy and Program Manager, Irene Bueno from NVG, Adam Carbullido from the Association of Asian Pacific Community Health Organizations (AAPCHO), Thaddeus Pham from the Hawaii Department of Health and Hep Free Hawaii, and Binh Ly, HBF #justB storyteller, led preparation for the meetings on Capitol Hill.*

During meetings with their representatives, advocates asked for support for: 1) the LIVER Act of 2019 2) increased National Institutes of Health funding to prioritize hepatitis B and liver cancer research, 3) increased Centers for Disease Control and Prevention funding for hepatitis B surveillance and prevention and, 4) prioritization of adult hepatitis B vaccination. Several states also informed their representatives of discriminatory drug tiering practices by insurance companies that are occurring within their state.



CONGRESSIONAL RECEPTION



Hep B Champions of 2019

Our annual Congressional Reception was held on July 23rd on Capitol Hill. Advocates heard remarks from *Representative Judy Chu*, *HBF's President and Co-founder Dr. Timothy Block*, and *AAPCHO Executive Director Jeff Caballero*. During the reception, Hep B United honored *Representative Grace Meng* with a Congressional Champion Award and four outstanding hepatitis B champions for their tireless efforts to improve the lives of those living with hepatitis B. The two recipients of the HBU 2019 Hepatitis B Champions Award were:

- **Richard Andrews**, co-chair of the National Task Force on Hepatitis B and Physician at HOPE Clinic in Houston, Texas
- **Xuan Phan**, #justB storyteller and hepatitis B case worker at Mercy Housing and Human Development in Gulfport, Mississippi

The Hepatitis B Foundation also presented two special service awards to:

- **Alan Brownstein**, who received the Lifetime Commitment Award for his dedication to addressing hepatitis B in the United States
- **Paula Wong**, who received the Community Commitment Award for her work on the Health + Education for Asian Livers (H+EAL) Project



SUMMIT: DAY ONE



CDC 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 with an overview of the current state of viral hepatitis in the U.S..The CDC has seen a spike in new hepatitis B cases in areas that have been deeply affected by the opioid crisis. The Division of Viral Hepatitis is continuing to fund community-based hepatitis B projects that focus on education, data collection, and linkage to care. They are also releasing two new culturally-sensitive PSA's in Chinese, Vietnamese, and Korean to encourage these populations to get tested! The PSA's are part of the Know Hepatitis B Campaign - a national multilingual media campaign in partnership with HBU. Be sure to look out for the new videos!



The Path to A Hepatitis B Cure

Dr. Timothy Block provided an overview of current scientific research regarding hepatitis B. Despite setbacks over the years, there are now a total of 30 investigational drugs being researched; HBF and the Baruch S. Blumberg Institute - HBF's research branch - are very active in the development of new drugs. The current drugs in development look promising. Some have shown dramatic reductions in hepatitis B surface antigen levels - a marker of hepatitis B that is essential to controlling the virus and a main cause of stigma and discrimination. Dr. Block predicts great advancements in treatment if we "keep the fire going" and stay dedicated!

Local Initiatives: Eliminating Hepatitis B Across the Lifespan

*Dr. Moon S. Chen from University of California - Davis, Liz Tang and Farma Pene from the New York City Department of Health & Mental Hygiene, and Chelsie Porter from the Hepatitis Education Project spoke about the successes and challenges of their diverse individual community-based projects. Dr. Chen focused on *Scratch B 2019* - an innovative project that uses an individual's surname in EMR systems to identify patients who have not been tested for hepatitis B and contacting their physicians to let them know to test their patient. Tang and Pene highlighted the *Hep B Moms Project*, which provides culturally appropriate patient navigation services two years postpartum to women living with hepatitis B, and Porter shared how her team is working towards integrating hepatitis B and C testing within syringe service programs.*



SUMMIT: DAY ONE



Integrating Systems Level Changes to Eliminate Hepatitis B

In this panel discussion, *Jeff Caballero from AAPCHO, Dr. Su Wang from the Center for Asian Health at Saint Barnabas Medical Center, and Dr. Richard Andrews, Research Director from HOPE Clinic* shared insights on what changes beyond the community level need to be made in order to work towards elimination. One of the main points of the discussion was the need for hepatitis B to be integrated into primary care practices. Dr. Wang shared the success of St. Barnabas Medical Center's implementation of automated screening for hepatitis B & C in their emergency department while Dr. Andrews shared his experience with ensuring follow-up care for those who are screened. Caballero discussed the utilization of PRAPARE - Protocol for Responding to & Assessing Patients' Risks & Experiences. PRAPARE is a national, standardized screening tool that engages patients in assessing and addressing social determinants of health.



Center for Disease Analysis Foundation - Study, Model, Eliminate

Devin Razavi-Shearer from the Center for Disease Analysis Foundation (CDAF) provided a keynote presentation on global hepatitis B efforts and models for elimination. The Foundation currently has several hepatitis B projects underway including identifying worldwide hepatitis B prevalence and creating an economic impact module. Their PRoGRess model has been used to track the global prevalence of hepatitis B as well as predict global and country-based trends for hepatitis B. Razavi-Shearer made the point that while financing options for hepatitis elimination plans do exist in many countries, governments need to step in to help make the options economically viable and encourage investments. Models, data, and accurate estimates are essential to creating effective policy and receiving the necessary resources to help vulnerable communities.



SUMMIT: DAY ONE

Breakout Sessions



Innovative Strategies to Conduct HBV Education, Testing, and Linkage to Care

In this session, *Paul Lee and Ohkyun Ko from Korean Community Services, Jane Pan from the Hepatitis B Initiative of Washington DC, and Alia Southworth from the Asian Health Coalition* discussed effective outreach strategies to conduct HBV education, testing, and patient navigation among high-risk communities. Key takeaways were that many minority community members preferred local doctors rather than a hospital, educating faith-based community leaders can aid in spreading messages, and stigma and fear are two major barriers to testing and data collection.

Increasing Provider Education

Dr. Amy Trang and Dr. Richard Andrews from the National Task Force on Hepatitis B provided insight on the development of provider education tools to aid in the management of chronic hepatitis B in the primary care setting. The leaders noted that primary care providers (PCP) are preferred by patients, not specialists. However, by connecting specialists with PCPs, as was modeled in Australia for hepatitis C, the treatment process can be much smoother and efficient. The National Task Force is launching a free Hepatitis B Care Guide in fall 2019 on the University of Washington's website to help PCPs and other providers provide the best care possible. The guide can be found at hepatitis.uw.edu this fall!

Combating HBV-Related Stigma & Discrimination

Vrushabh Shah from NASTAD and Nadine Shiroma, and Alexa Canizzo from HBF explored the impact of HBV-related stigma and the development of policies to combat institutional discrimination. Panelists talked about the populations that were most burdened by stigma, including those in institutional settings like the U.S. military and health professions schools. HBF has taken action by making sure that individuals are aware of their rights, working with their cases as they fight back against discrimination, and working with institutions to make them aware of their discriminatory policies and encourage them to create more inclusive standards.

Local, National, & Global Efforts to Increase HBV Testing & Education Among African Communities

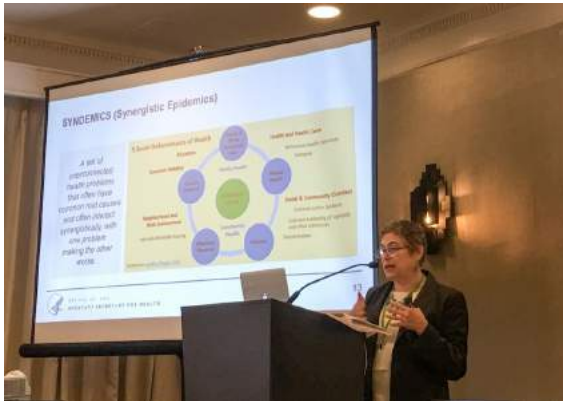
Oni Richards from the African Family Health Organization (AFAHO), Chioma Nnaji from the Multicultural AIDS Coalition (MAC), and Sierra Pellechio and Catherine Freeland from HBF presented on their work in African immigrant communities. Along with HBF, AFAHO has been educating and screening Philadelphia's African Immigrant population as well as linking them to care. Nationally, MAC has been working to bring attention to the African communities' need for hepatitis resources and support by advocating for federal recognition of National African Immigrant and Refugee HIV and Hepatitis Awareness (NAIRHHA) Day. HBF is also partnering with the CDC to develop tools to promote hepatitis B awareness and testing within the communities. Development is currently in the second of three phases.

SUMMIT: DAY TWO



National Action Plan to Eliminate Hepatitis B

Carol Jimenez from the U.S. Department of Health & Human Services' Office of Infectious Disease and HIV/AIDS Policy provided federal insight into the development of the next National Viral Hepatitis Strategic Plan that is set to be released in 2020. The new plan will address the role of the social determinants of health. However, stronger local efforts and community involvement are needed to create comprehensive elimination plans within their communities. "The data shows that there are health disparities," said Jimenez, "We need to do more to address viral hepatitis in the United States".



Global Efforts to Eliminate Hepatitis B

Dr. Su Wang from the World Hepatitis Alliance (WHA) and Dr. Nick Walsh from the World Health Organization (WHO) spoke to summit attendees about the successes of the global campaign to eliminate hepatitis and what work still needs to be done. Although organizations around the world are participating in elimination efforts, funding remains one of the largest barriers to action, in addition to low global diagnosis rates. The teams at WHA, WHO, and NOhep are focused on strengthening civil society's role in elimination in an effort to address lack of awareness. Currently global health organizations are calling for a 90% reduction in new chronic infections by 2030. To achieve this, a comprehensive effort from advocates, patients, and policymakers is essential.



Patients Driving Change

Since its creation in 2017, #justB - a national, multilingual storytelling campaign - has held 5 workshops, participated in 8 local screening events nationwide, created 40 digital stories - of which 18 have been translated into 14 languages - and has been viewed online over 2 million times! The videos act as both an educational tool for those who may be unfamiliar with hepatitis B, and as a way for those living with it to share their voice. During this session, several of HBU's storytellers shared their moving, inspirational stories and displayed the power of speaking up about hepatitis B.



SUMMIT: DAY TWO



Improving Access to Hepatitis B Treatment

Access to hepatitis B treatments is becoming increasingly difficult for those living in the United States. *Michaela Jackson from HBF* explained how insurance companies in various states are purposefully creating an economic burden for those requiring treatment. *Alyssa Gallipani from RWJ Barnabas Health & Fairleigh Dickinson University* broke down how drugs were priced, what it meant for the consumer, and financial resources that providers can share with their patients. *Carl Schmid from The AIDS Institute* wrapped up the panel session by describing copay accumulators and how they can drive up the cost of medication for a consumer. "As patients' out-of-pocket costs go up," said Carl "people abandon their medications."



Eliminating Tuberculosis in Asian American Communities

Nickolas DeLuca from the CDC's Division of TB Elimination spoke about latent TB infection (LTBI) and TB disease. LTBI has no symptoms and the infection cannot be spread to others. Approximately 51% of all TB cases in the United States can be found in California, Texas, New York, and Florida; a majority of TB infection are found in people born outside of the United States. CDC's Division of TB Elimination is looking to HBU as a model for expanding their outreach methods.



Hep B United Coalition Strategies

In the final session of the 2019 summit, *Amy Trang from the National Hep B Task Force and HBF's Kate Moraras* facilitated a discussion centered around the next steps for the coalition. Summit attendees offered feedback on programming and brainstormed how HBU can further assist its members. Suggestions included creating dissemination tools for treatment access issues, providing more information about data collection and analysis, establishing a training program for new coalition leaders, and identifying ways to reach new communities such as the South Asian and LGBTQ communities.





Research Exhibit

For the first time ever, HBU held a poster exhibit at the summit! The exhibit gave our partners an opportunity to share their research with peers, and identify potential collaborators for future research endeavors. The list of researchers and their posters are below; please feel free to reach out to them for more information about their projects!

Presentations

- **World Hepatitis Day Awareness Campaign for High Risk Population.** Prakash Kotecha, Asian Pacific Community in Action.
- **Hepatitis B Case Studies on the Mississippi Gulf Coast.** Tanya T. Funchess DHA, MPH, MSM Danielle Fastring, PhD, MS, MPH, Xuan Phan, Kiet Nguyen.
- **Prevalence of Chronic Hepatitis B and C Infection in Mongolian Immigrants in the Washington, District of Columbia, Metropolitan Area, 2016–2017.** Jane Pan, Emmeline Ha, MD; Frederic Kim, MS; Janice Blanchard, MD, PhD, MPH; Hee-Soon Juon, PhD. HBI-DC.
- **Towards Viral Hepatitis Elimination: An Innovative Strategy to Screen At-Risk Populations in the Emergency Department with Linkage to Primary Care.** Binghong Xu, MD, Ruth Brogden, MPH, Elaine Zhai, DO, Mindy Houng, MD, Shih-Fen Chow, MD, Alyssa Gallapani, PharmD, BCACP, Eka Beriashvili, PharmD, Nicole Barberio, MHA, Briana Mercantonio, MHA, Wen-Chi Chen, MA, Su H. Wang, MD, MPH. St Barnabas Medical Center, Center for Asian Health.
- **Evaluation of Hepatitis B and C Prevalence via Community Health Outreaches in San Diego.** Kayla Giang, Pharm.D., M.S., Binh Tran, Pharm.D., M.S., M.B.A., Nguyen Vo, Thu Vuong, James Pham, Andrew Liu, Ph.D., Megan Cheng, James Cordero, Vivian Ngo, Tam Ho, Kevin Lam, Danh Truong, M.D. Robert Gish, M.D., Palmer Taylor, Ph.D. Asian Pacific Health Foundation.
- **Hep B Free Los Angeles (HBLA) Expanded Activities in Southern California.** Binh Tran, PharmD, MS, MBA; Koy Parada, PhDc, MPH; Mimi Chang, DNP. Hep B Free Los Angeles
- **Surveillance-based estimate of chronic hepatitis B prevalence, New York City, 2016.** Nirah Johnson, Natalie Octave, Meg Chappell, Jessie Schwartz, Ann Winters. NYC Health Department.

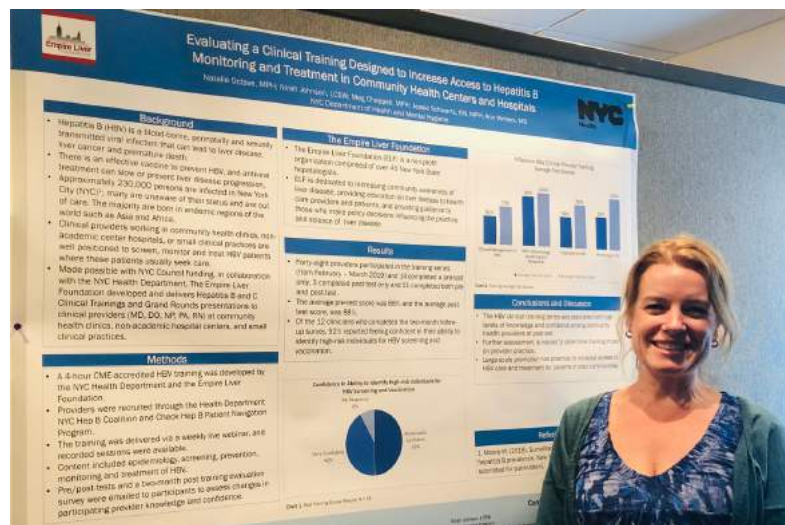


Hepatitis B Case Studies on the Mississippi Gulf Coast



Presentations

- **NYC Department of Health and Mental Hygiene Check Hep B Patient Navigation Program.** Umaima Khatun, Johnson N, Schwartz J, Winters A. NYC Department of Health and Mental Hygiene.
- **Surveillance-based estimate of chronic hepatitis B prevalence, New York City, 2016.** Nirah Johnson, Natalie Octave, Meg Chappell, Jessie Schwartz, Ann Winters. NYC Health Department.
- **Development of the Somali Health Advisory Committee to Address the Needs and Concerns of Somalis.** Living in Midwestern United States. Fowsiyah Ahmed, Nasra Giama, Naima Yusuf, Essa Mohamed, Hamdi Ali, Abdirashid Shire, & Lewis Roberts. Mayo Clinic.
- **A Community based study for promoting activities to reduce Hepatitis B consisting 10 members picked up from the community those who are already aware about the dangerous consequences of Hepatitis B.** Mohammed Islam, Hong Liu PhD. Community Welfare Services of Metro Detroit (CWS).
- **Evaluation of “Focus on HBV” through HALO’s Academy for Medical Assistants.** Moon Chen, Jr. PhD, MPH, Alexandra Gori, Duke LeTran B.S., George Yang B.S., Mary Pat Pauly, MD, FAASLD, FACP, Amy Beste-Fong, RN, MCM, Kit W. Tam MD, Ian Johnson MD. UC Davis Comprehensive Cancer Center.
- **Linkage to care of postpartum women in New York City.** Liz, Tang, Farma Pene, Jessie Schwartz, Nirah Johnson, Ann Winters. New York City Department of Health and Mental Hygiene.



Surveillance-based estimate of chronic hepatitis B prevalence

Final Thoughts



World Hepatitis Day 2019

Each year, World Hepatitis Day is observed on July 28th. This year, HBU asked summit attendees to help raise awareness by creating a Hep B United "Hepatitis B Elimination Map"! The large, interactive map displayed photos of communities around the U.S. working to address hepatitis B. The map was the central piece of HBU's World Hepatitis Day exhibit on Capitol Hill. Visitors stopped by the display to learn about hepatitis, elimination efforts, and how they could help find the missing millions!



Final Thoughts



Conclusion

Hep B United's seventh 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!



Hep B United
Hepatitis B Foundation



@HepBUnited
@HepBFoundation



Hep B United
Hepatitis B Foundation



@HepBUnited
@HepBFoundation





#HEPBUNITE19