Hep B United National Summit Report
July 27-29, 2016

Washington, D.C.

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Introduction and Summit Goals

The 4th Annual *Hep B United National Summit* was held in Washington, D.C. July 27-29, 2016, coinciding with World Hepatitis Day events. Over 50 individuals from 37 partner organizations attended, including representatives from community organizations, health clinics, academic institutions, and federal agencies. The *Hep B United National Summit* is designed to serve as a coalition strengthening opportunity for partners to engage at multiple levels and share experiences and best practices with one another. In addition, the Summit fosters collaboration among coalition partners.

Each annual Summit is designed to advance our movement to address hepatitis B, and plan for the future. In 2016, partners focused on the accomplishments of the Centers for Disease Control and Prevention (CDC) *Know Hepatitis B Campaign* and discussed the current state of hepatitis B in the country. Summit activities focused on increasing capacity at the local and national levels, liaising with federal partners, building future collaborations, and sharing best practices for community-based education, screening and linkage to care. The overall objective for the Summit is to work towards the goals of Hep B United.

Overall Goals of Hep B United:

- Raise the profile of hepatitis B and liver cancer as an urgent public health priority.
- Increase hepatitis B testing and vaccination, particularly among Asian Americans, Pacific Islanders, and other at-risk communities.
- 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 and 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 26 cities and 15 states, including the District of Columbia, HBU has a reach of over 4 million Asian Americans and Pacific Islanders. Each year, HBU partners conduct over 13,000 educational sessions, screen over 40,000 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 CDC program led by Cynthia Jorgensen, DrPH. The co-branded campaign, which provides multi-lingual tools and resources for local coalitions, represents a successful ongoing partnership between HBU and the CDC Division of Viral Hepatitis.

The Summit itself works towards planning for the future of the HBU Coalition. In 2016, a coalition-focused discussion challenged members to think about where HBU should orient itself moving forward. Priorities discussed during a team building exercise were aimed at increasing feedback and communication between community members and HBU leadership, in addition to expanding the enthusiasm generated at the Summit to community members locally, and creating an orientation process for new coalition members in the future.

The State of Hepatitis B

*Dr. Brian McMahon, MACP, FAASLD, Medical Director, Liver Disease and Hepatitis Program, Alaska Native Tribal Health Consortium***,** provided an update on the current status of hepatitis B nationally and globally. In 2010 it was estimated that there were 1 million cirrhosis deaths worldwide and 31% of countries had no data to contribute to this statistic. Dr. McMahon noted the need for more accurate data in order to effectively address gaps in linkage to care. He also noted gaps in screening and provided recommendations to increase screening worldwide through HIV piggyback programs and suggested the need for more innovative strategies for training healthcare workers internationally.

> "There is a need for more accurate data in order to effectively address gaps in linkage to care"
> *Dr. Brian McMahon*

Data and Linkage to Care

Dr. McMahon's discussion surrounding the need for accurate data to address linkage to care directly corresponds with presentations provided within Summit breakout sessions. During small group sessions, coalition members shared personal experiences on navigating patients, linkage to care strategies and leveraging data and evaluating impact. The gap in data collection nationally is a substantial issue surrounding hepatitis B and allows for it to be under-estimated and under-prioritized in the U.S. Expanding on 2014's HBU Summit goal to increase data collection, the coalition continues to stress the importance of working together to prioritize national data infrastructure to consolidate the data we currently have. In addition, the importance and value of qualitative data was noted in that it allows for us to develop a robust picture of our communities and their experiences with hepatitis B.

Finding more ways to analyze and use the data we have can ultimately help lead to a reduction in gaps within patient navigation and linkage to care. A key strategy used to expand linkage to care in Columbus, Ohio was engaging multiple stakeholders through provider education sessions in order to expand patient navigation and linkage to treatment. This included reaching out to providers at multiple levels including community leaders, board members, physicians, and medical students to expand education on hepatitis B. As a result, three hospitals in Columbus have incorporated alerts for hepatitis B screening into their electronic health record system. The *Check Hep B Program* used in New York City (soon to be piloted in Hawaii) expands navigation and care coordination by engaging multiple clinic sites throughout the city. Both the *Check*

Hep B Program and the Columbus, Ohio program expand on linkage to care and provide further examples for coalition members to learn from and work towards within their own communities.

Expanding Partnerships and Sustaining Local Coalitions

Expanding our reach through new partnerships and continuing to build and sustain local hepatitis B coalitions are priorities within the HBU Coalition. In order to expand partnerships, coalition members shared personal experiences on how to reach non-traditional partners, including the Asian American small business and corporate communities. Coalition members encouraged others to move out of their traditional comfort zone and expand their circles through networking. Finding common ground, interest, and understanding the populations served can allow for contribution to a potential partners quality measures while expanding resources for the good of the community.

The value of building and sustaining local hepatitis B coalitions was discussed through members' personal experiences and lessons learned. Focus was placed on developing strategies to sustain local hepatitis B coalitions and learn about engaging staff and local leadership. Members also suggested a benefit for future advocacy involves creating and expanding relationships with academic institutions to build innovative programs with undergraduate students to establish a pipeline for professionals with an understanding of hepatitis B.

World Hepatitis Day

July 28th began with a discussion of Federal Leaders and coalition members through the U.S. Department of Health and Human Services (HHS) *Town Hall Meeting on Hepatitis B*. This meeting allowed for federal partners to update coalition members on their current efforts to address hepatitis B.

- **Richard Wolitski, PhD, Acting Director, HHS Office on HIV/AIDS and Infections Disease Policy** provided opening remarks and welcome to the coalition members and federal partners.
- **Corinna Dan, RN, MPH, Viral Hepatitis Policy Advisor, HHS Office on HIV/AIDS and Infectious Disease Policy** provided commentary and moderation for the town hall meeting
- **Jono Mermin, MD, MPH, Director, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, CDC** stated the need to focus on social determinants and inequality in order to work towards preventing HBV infections and decreasing negative health outcomes.
- **Carol Jimenez, JD, Deputy Director, HHS Office of Minority Health** said she appreciates the partnership between the coalition and federal partners, and provided statistics noting the existing disparities, which OMH is "actively working to call attention and reduce disparities to ensure Americans have quality health care."

- **Nicole Smith, PhD, MPH, MPP, Associate Director, Policy Office, CDC Division of Viral Hepatitis,** noted the importance of ensuring vulnerable populations have access to vaccination and identifying those living with viral hepatitis early.
- **Sarah Schillie, MD, MPH, MBA, Medical Officer, CDC Division of Viral Hepatitis,** identified three top priorities: (1) Improve identification of hepatitis B mothers, (2) improve rates of post-serologic infection testing, and (3) improve data collection to describe patterns of perinatal transmission.
- **Laura Makaroff, DO, Senior Clinical Advisor, Office of Quality Improvement, Bureau of Primary Health Care, Health Resources and Services Administration,** noted priorities were to increase access to high quality health care services, modernize infrastructure of primary care, improve health outcomes, work with partners, and promote innovation.
- **Susana Lorenzo-Giguere, JD, Trial Attorney, Disability Rights Section, Civil Rights Division, U.S. Department of Justice,** stated that, “hepatitis discriminations are a civil rights issue.”
- **Kimberly Konkel, MSW, Associate Director, Center for Faith-Based and Neighborhood Partnership, HHS,** noted the importance of education and building health literacy among highly affected communities.

Following the town hall meeting, coalition members implemented their advocacy training during the Summit to **advocate for prioritization of hepatitis B on Capitol Hill**. The coalition made visits to 25 Congressional offices with clear priorities that included the following: (1) thank Members for their support and discuss the importance of increased screening, vaccination and research for hepatitis B and liver cancer; (2) ask for federal prioritization and increased appropriations for hepatitis B; and (3) invite Members to join the Congressional Hepatitis Caucus. Coalition members found Congressional staff to be quite receptive and interested in championing hepatitis B. Throughout the year, HBU will continue to work on advocacy efforts to address priority issues. As hepatitis B advocates, it is more important than ever to raise our voices to federal decision makers about the need for increasing federal attention and investment in hepatitis B research and public health.

Hep B Champions 2016

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

- **Alex Shirreffs** of the Philadelphia Department of Health was recognized for her collaboration with Hep B United Philadelphia to screen local Asian American and Pacific Islander communities and her commitment to ensuring hepatitis B remain a public health priority into the future.
- **Hepatitis B Coalition of Washington State** was recognized for their commitment to the Seattle and Washington State Asian American and Pacific Islander

communities by bringing together stakeholders from across the state and providing screening, education and linkage to care for thousands of individuals.

- **Nadine Shiroma**, a hepatitis B civil rights advocate, was recognized for her ongoing leadership towards eliminating hepatitis B-related discrimination.
- **Dr. Moon Chen of the National Center for Reducing Asian American Cancer and Health Disparities at U.C. Davis**, was recognized for continuing to make hepatitis B a priority for academic and public health research, so that we have the tools we need to appropriately address hepatitis B in the U.S.

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 2016 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.