Statement of

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The Association of Asian Pacific Community Health Organizations (AAPCHO) is a national association representing 27 community health organizations founded in 1987. For more than 20 years, AAPCHO has advocated for the provision of health care services that are community driven, culturally appropriate, linguistically accessible, and financially affordable for all. For more information and AAPCHO's Guiding Principles and Values, please visit www.aapcho.org.

The Asian & Pacific Islander American Health Forum (APIAHF) was formed in 1986, to address health disparities in Asian American, Native Hawaiian, and Pacific Islander communities and has since worked with community advocates, public health leaders and policymakers to mobilize communities, strengthen programs and organizations and generate policy and systems changes that benefit our communities at the national, state and local levels.

Thank you for giving AAPCHO and the APIAHF the opportunity to provide testimony to the Committee and for holding this very important hearing. A Congressional hearing on viral hepatitis will help bring much needed attention and focus to the issue of prevention and control of chronic hepatitis B and C. Please know that although this statement will focus specifically on the needs and recommendations for chronic hepatitis B, most of what is written is also relevant to helping to solve the problem of chronic hepatitis C in this country as well.

The problem of Hepatitis B in Asian American, Native Hawaiian, and other Pacific Islander (AA & NHOPI) was brought to the attention of AAPCHO's Board of Directors by our member health organizations when they were challenged with this growing problem for the patients they serve. Finding little information or resources to assist their programs in developing culturally competent, comprehensive hepatitis B programs to serve patients, they requested support from AAPCHO in the form of technical assistance and advocacy.

Hepatitis B and Asian American, Native Hawaiian, and other Pacific Islanders

Approximately 350 million people worldwide are infected with hepatitis B, a deadly disease that often goes undetected despite the fact that it causes about 80% of all primary liver cancers. Hepatitis B, a liver disease caused by the hepatitis B virus (HBV), can lead to lifelong infection, scarring of the liver, liver cancer, and death. In the U.S., it is estimated that 1 in 20 people will become infected with HBV, and 1 in 4 chronic hepatitis B carriers will die of liver cancer or liver failure.

Within AA & NHOPI populations, this "silent disease" has had an especially devastating health impact. AA & NHOPIs comprise more than half of the 2 million estimated hepatitis B carriers in the United States and, consequently, have the highest rate of liver cancer among all ethnic groups.

Although infection is preventable with a safe and effective hepatitis B vaccine, many people live with (and often unknowingly pass on) this chronic disease. Compounding this problem, hepatitis B screening and vaccination rates among AA & NHOPIs are alarmingly low, given the disease's disproportionate affect on this population. For example, a 2005 study done in

New York City found that more than half (56.6%) of AA & NHOPIs had not been previously screened for HBV and 15% of those unscreened individuals were indeed chronically infected with HBV.

Because many chronic HBV patients show no symptoms and are generally healthy, the disease progresses, is transmitted unknowingly, and often leaves individuals in the late stages of liver cancer or liver disease without warning, too late for medical intervention. It is critical that AA & NHOPIs get screened and vaccinated for HBV and those individuals who have been exposed to HBV receive appropriate, ongoing medical care. Increasing the availability of culturally and linguistically appropriate HBV programs will help lower existing barriers that prevent this population from accessing services, from screening and vaccination to disease management and treatment. We must also educate health care providers on the prevalence of HBV among AA & NHOPIs, and replicate successful community-based programs that prevent and manage HBV in these populations.

Hepatitis and the Public Health Infrastructure

The U.S. Center for Disease Control and Prevention's (CDC) Division of Viral Hepatitis received only \$19.3 million in FY2010 for hepatitis prevention and control, which represents less than 2% of the budget of CDC's National Center of HIV/AIDS, Hepatitis, STD, and TB Prevention. This is the only dedicated funding for prevention that the federal government gives to hepatitis. CDC needs a robust infusion of resources to effectively carry out its mission. States and cities receive \$5 million total that averages to \$90,000 per jurisdiction. This is only enough for a single staff position and is not sufficient for the provision of core surveillance and direct care services. These services are essential to preventing new infections, increasing the number of people who know they are infected, and following up to help those identified to remain healthy and productive. An increase in this funding is an important first step to making hepatitis prevention services more widely available. The expanded services should include hepatitis B and C education, counseling, testing, and referral in addition to delivering hepatitis A and B vaccine, and establishing a surveillance system of chronic hepatitis B and C that captures detailed data on race ethnicity in order to understand the epidemics and thus target scarce resources most effectively.

The CDC National Center for Immunization and Respiratory Diseases identified funds through program cost savings in the Section 317 Vaccine Program, allocating \$20 million in FY2008 and \$16 million in FY2009 for purchase of the hepatitis B vaccine for high-risk adults. AAPCHO commends CDC for prioritizing high-risk adults with this initiative, but relying on the availability of these cost savings is not enough. In addition, this initiative does not support any supplies, infrastructure or personnel and health departments and community organizations need additional funding to support the delivery of vaccine. There must be a continuation of funding in FY2011 for an adult hepatitis B vaccination initiative through the CDC's Section 317 Vaccine Program.

The CDC should provide additional resources and guidance to Perinatal Hepatitis B Prevention Program Coordinators to expand and enhance their capacity to identify

chronically infected pregnant women and provide case-management services, including referral for appropriate medical management. Currently, this program is funded to ensure that infants of mothers with chronic HBV receive appropriate vaccination at birth and complete the series of three doses. A major opportunity is missed when the mothers are not referred to care for their HBV and household contacts are not referred for testing and vaccination when appropriate. This type of basic public health approach has been effective when accurate testing and safe and effective vaccine is available as is the case with HBV and has been shown by the eradication of small pox globally and polio in the western hemisphere. Additional outreach, education and referral for medical management would increase the proportion of individuals chronically infected with HBV who are in care and substantially reduce the risk of liver disease and liver cancer.

Hepatitis and Community Health Centers

Currently, there is no funding and very little guidance for community health centers to provide hepatitis B and hepatitis C services for their patients. The Health Resources and Services Administration (HRSA) should provide adequate resources to federally funded community health centers for provision of comprehensive viral hepatitis services in addition to leadership and guidance for these health centers which are accessible and provide low cost health services in communities that serve individuals with chronic hepatitis. Additionally, HRSA and the CDC should provide resources and guidance to integrate comprehensive viral hepatitis services into settings that serve high-risk populations.

Community health centers, including AAPCHO's member centers have developed culturally competent health care environments which are well suited to provide care for long term chronic diseases such as hepatitis B and hepatitis C. Their staff are often from the community and services are developed in response to the needs of patients. Leadership and resources are sorely needed to further develop and expand model programs such as the one at the Charles B Wang Community Health Center in New York City. This model program works with community outreach and public health, accepting referrals from screening and perinatal programs, providing culturally and linguistically appropriate care. With additional support, this type of program can be shared with other health centers serving hepatitis patients to address their unmet HBV care needs.

Community health centers should also receive support to implement hepatitis B awareness and advocacy activities within the communities at risk that they serve. Hepatitis B awareness is very low in the general public and more robust partnerships are necessary in order to raise awareness to fully address HBV. Community health center leadership is critical to developing networks of community based, culturally and linguistically competent organizations, in order to raise awareness and increase advocacy activities. However, additional resources and guidance are needed to make these efforts successful.

The new health reform law holds opportunities to expand access to health care services for people living with hepatitis. The new law removes pre-existing condition exclusions that have been a barrier for people living with chronic hepatitis B and C. The Medicaid

expansion in 2014 will allow greater access to care and treatment for low-income people with hepatitis. The law also expands access to vaccines for adults, which will help close the hepatitis A and B vaccine gap. The challenge remains of expanding access to screening for hepatitis B and C which we urge the Secretary of Health to include in the minimum insurance benefits package for prevention. An additional opportunity in the law to fund hepatitis prevention services is the Prevention and Public Health Fund. We have appealed to HHS to include hepatitis as eligible for these funds. We believe it will be an enormous missed opportunity if hepatitis, one of the most underfunded, costly chronic infectious diseases is excluded.

Need for Improved Hepatitis Policies, Increased Funding and Continued Leadership

The Institute of Medicine's (IOM) recent report, <u>Hepatitis and Liver Cancer: A National</u> <u>Strategy for Prevention and Control of Hepatitis B and C</u>, is a critical opportunity for the federal government to finally address hepatitis B and C through the implementation of its recommendations, most of which are directed at HHS. The report attributes the profound ignorance among the American public and providers, the large health disparities and the current hepatitis morbidity and mortality, to the lack of adequate financial resources and further recommends improved coordination of federal programs.

AAPCHO and the APIAHF commend the new Assistant Secretary for Health, Dr. Howard Koh, for his role in leading the HHS response to the hepatitis epidemics by convening an interagency workgroup representing key stakeholders across the HHS agencies in order to prioritize and coordinate hepatitis activities. We hope that the workgroup will be able to improve coordination and prioritization of hepatitis activities across all HHS agencies, implement the IOM's recommendations, raise the level of awareness and leadership within HHS and the Administration, and develop a national strategy on hepatitis. AAPCHO urges increased support for this important initiative and increased funding levels for the CDC Division of Viral Hepatitis up to \$90 million.

Policymakers must be made aware of the consequences of continued inaction. Chronic hepatitis B and the resultant liver cancer and advanced liver disease among AA & NHOPIs is a leading cause of death and 10% remain chronically infected. Even with a safe and effective vaccine against hepatitis B, 5,000 Americans will die and approximately 1,000 babies will still be infected at birth every year. The costs to the healthcare system generated by liver disease associated with chronic hepatitis B infection costs an estimated billion dollars per year.

In addition to increasing funding, Congress needs to pass the Viral Hepatitis and Liver Cancer Control and Prevention Act (H.R. 3974). This legislation, which was co-authored by Chairman Ed Towns, authorizes a comprehensive prevention, education, surveillance, research and medical management referral program to understand and reduce the disease burden associated with hepatitis infections, and includes the development of a national plan. Congress should also help raise the level of awareness of hepatitis by passing the World Hepatitis Day and Month of May as National Hepatitis Awareness Month Resolutions (H.RES.1302, S.RES.531).