



Testimony for Submission

National Alliance of State and Territorial AIDS Directors

To the House Committee on Oversight and Government Reform
For the Hearing "Viral Hepatitis: The Secret Epidemic."

June 17, 2010

The National Alliance of State and Territorial AIDS Directors (NASTAD) commends the House Committee on Oversight and Government Reform for holding the hearing "Viral Hepatitis: The Secret Epidemic." Today's hearing is the first time Congress has formally examined the federal response to viral hepatitis since December 2004.

Founded in 1992, NASTAD is a not-for-profit membership organization representing the nation's chief state health agency staff that have responsibility for administering both HIV/AIDS and viral hepatitis programs funded by state and federal governments. NASTAD is dedicated to reducing the incidence of HIV/AIDS and viral hepatitis infections in the U.S. and its territories through providing prevention; education; comprehensive, compassionate, and high-quality care to all persons living with HIV/AIDS and viral hepatitis; and ensuring responsible public policies exist to support this commitment.

We are submitting testimony for the record that addresses the challenges facing public health in addressing the viral hepatitis epidemics and the needs of those chronically infected. A recent Institute of Medicine (IOM) report [*"Hepatitis and Liver Cancer: A National Strategy for Prevention and Control of Hepatitis B and C"*](#) highlights a troubling lack of knowledge among health-care and social-service providers, at-risk populations, the general public and policy makers about the devastating impact of viral hepatitis. The report concludes that inadequate public funding for viral hepatitis prevention, control and surveillance programs is an apparent cause.

Overview of the Domestic Viral Hepatitis Epidemics

Due to the lack of a national chronic viral hepatitis surveillance system, much of the hepatitis data published by the Centers for Disease Control and Prevention (CDC) do not provide an accurate picture of the magnitude of chronic hepatitis B virus (HBV) and hepatitis C virus (HCV) infection in the United States (U.S.). An often quoted statistic that 1.8 percent of the U.S. population, or 3.2 million Americans, are infected with HCV,

comes from the National Health and Nutrition Examination Survey (NHANES). While this is a trusted source of statistical health information, NHANES does not include data on populations bearing a disproportionate burden of chronic HCV infection such as persons incarcerated, in substance use treatment facilities and those who are homeless or marginally housed. Taking this into account, the 1.8 percent estimate derived through NHANES is considered by most experts to be a misleading underestimation.

Even with no national chronic viral hepatitis surveillance system, CDC estimates are astounding. It is estimated that 5.4 million Americans have chronic HBV and HCV infection. In 2007 alone, it is estimated that 43,000 Americans were newly infected with HBV and 17,000 with HCV. Unfortunately, it is believed that these estimates are also just the tip of the iceberg.

Racial and ethnic minorities, persons who inject drugs, gay and bisexual men and HIV-positive individuals continue to bear the brunt of this epidemic. African Americans, Asian Americans, Pacific Islanders, Native Americans, and Alaskan Natives have the highest rates of hepatitis A, B, and C infection in the U.S. Persons born in HBV-endemic areas of the world, persons born to mothers from HBV endemic areas, HIV infected persons, gay/bisexual men, and persons who inject drugs bear the greatest burden of new HBV infections in the U.S. African Americans have the highest rate of acute hepatitis B infections in the United States. Chronic hepatitis B is a leading cause in death in Asian Americans, with as many as 1 in 10 living with chronic hepatitis B. Persons who inject drugs bear the greatest burden of new HCV infections in the U.S. Some studies estimate that the prevalence rate of HCV among persons who inject drugs could be as high as 90 percent in some cities. Similar studies indicate that the longer an individual injects drugs, the higher likelihood that he or she will become infected with HCV within five years. African Americans and Hispanics have higher rates of hepatitis C infection than Caucasians. In addition we are seeing a marked increase of sexual transmission of hepatitis C among HIV-positive gay/bisexual men and an emergence of hepatitis C infections among those under the age of 25 largely due to heroin use. This is a striking increase over previous years where the majority of cases were largely in populations over the age of 40 years.

Many people with chronic HBV and HCV are unaware that they are infected because HBV and HCV are often asymptomatic until advanced liver damage has developed. It is estimated that up to 65 percent with chronic HBV and 75 percent with chronic HCV are unaware of their status. Without knowledge of status, an individual cannot receive timely treatment or make life changes to stem the progression of disease, such as cessation of alcohol consumption, eating a healthy diet, and regular exercise. Without knowing they are infected, persons with HBV and HCV may also unknowingly transmit the viruses to others.

Each year, 12,000 Americans die from HCV related liver disease and 3,000 die from HBV related liver disease. In addition, chronic viral hepatitis is the leading cause of liver cancer, one of the few cancers on the rise and now among the top ten killers of Americans over the age of 25 years. HCV is the most common cause of chronic liver disease in the U.S., accounting for 40 to 60 percent of all cases. Most liver transplants in the U.S. are due to complications of chronic HCV. Many of these expensive procedures could be averted through initiatives that educate those at risk and diagnose and treat those who are chronically infected. Without increased resources for counseling, testing and medical referral services, HCV-related deaths and long-term complications are projected to increase dramatically by the year 2020: liver failure by 106 percent, liver cancer by 81 percent, and liver-related deaths by 180 percent. Additionally, 25 percent of people living with HIV/ AIDS are also infected with HCV and up to ten percent are also infected with HBV. Chronic viral hepatitis is a leading killer of Americans living with HIV/ AIDS.

Failure to address viral hepatitis has enormous consequences. HBV infections result in an estimated \$658 million in medical costs and lost wages annually. Without intervention, the HCV epidemic is expected to result in 3.1 million years of life lost over the next decade. The projected direct and indirect costs of the current HCV epidemic, if left unchecked, will be over \$85 billion for the years 2010 through 2019. Most of these costs will be absorbed by Medicare given that an estimated two-thirds of Americans living with chronic HCV are baby boomers who remain unaware of their infection and will be aging onto Medicare with liver cancer and liver disease.

Role of Public Health in Viral Hepatitis

Public health agencies are entrusted through U.S. law as the central authorities of the nation's public health system and, as such, bear the primary public sector responsibility for health. State public health responsibilities include disease surveillance; epidemiology and prevention; provision of primary health care services for the uninsured and indigent; and overall planning, coordination, administration, and fiscal management of public health services. State public health agencies serve an essential and unique role in the coordination and delivery of viral hepatitis services. Because of the lack of federal guidance, leadership, and support for state and local viral hepatitis programming, public health agencies are severely challenged in carrying out their important role as protectors of their constituents' health.

Importance of Health Departments in the Nation's Public Health Response to Viral Hepatitis

Health departments were first funded by the CDC Division of Viral Hepatitis (DVH) in 2000 to provide coordination of services for individuals at risk for and infected with HCV. In 2007, CDC DVH redefined the role of health department "HCV Coordinators" to focus more broadly on adult viral hepatitis, creating the position of "Adult Viral Hepatitis Prevention Coordinator" (AVHPC) in all funded jurisdictions, currently 55,

including 49 states, the District of Columbia and five directly-funded cities – Chicago, Houston, Los Angeles County, New York City, and Philadelphia.

Funded jurisdictions received an average award of \$90,000 in FY2010 to establish and maintain an AVHPC with the technical expertise necessary for the management and coordination of activities directed toward preventing viral hepatitis infections. This includes identifying, counseling and referring individuals infected with chronic HBV or HCV infection for medical management, as well as integrating viral hepatitis prevention services into health care and public health services for adults at risk for viral hepatitis. The AVHPC is the public health professional in each jurisdiction responsible for:

- Developing a viral hepatitis prevention plan that integrates core viral hepatitis prevention services, including HBV and HCV counseling and testing, into existing programs;
- Adult HAV/HBV prevention programming for at-risk adults;
- Training for professionals serving at-risk adults;
- Referral to substance abuse treatment for persons who use injection- or non-injection illicit drugs;
- Services for HIV-infected persons, including hepatitis A virus (HAV)/HBV vaccination of all susceptible persons and testing to identify HIV-infected persons with chronic HCV infection or chronic HBV infection; and
- Monitoring and evaluating delivery of viral hepatitis prevention services.

With the current level of federal funding, health departments cannot support these and other core public health services. The CDC DVH cooperative agreements with health departments only provide funding for the one full time position and required travel to an annual CDC DVH grantee meeting.

Within health departments, AVHPCs are located in different sections, including HIV/AIDS, sexually transmitted disease (STD), and tuberculosis (TB) programs; immunization programs; and communicable disease programs. This often offers AVHPC the opportunity for cross-program collaboration and integration of viral hepatitis services into other areas of public health. Because funding for health department viral hepatitis programs is inadequate, collaboration and integration are essential to the provision of the most basic services.

In addition to the AVHPCs, CDC's Immunization Services Division (in the National Center for Immunization and Respiratory Diseases) funds "Perinatal/HBV Coordinators" in 66 jurisdictions, including 50 states; the District of Columbia; eight directly-funded cities - Chicago, Detroit, Houston, Los Angeles County, New York City, Philadelphia, San Antonio and Washoe County, NV; and eight territories including America Samoa, Federated States of Micronesia, Guam, Marshall Islands, Commonwealth of the Northern Marianas Islands, Puerto Rico, Palau and the U.S. Virgin Islands.

Funding for health department perinatal/HBV programming is included in a larger immunization cooperative agreement to grantees. Perinatal/HBV Coordinators play an important role in the coordination of services and are responsible for:

- Identifying all HBsAg-positive women;
- Conducting case management of all identified infants at risk of acquiring perinatal HBV infection;
- Reporting of HBsAg-positive infants and providing appropriate care to infants born to mothers of unknown HBsAg status;
- Developing a state plan to put into practice a universal reporting mechanism with documentation of maternal HBsAg test results for all births; and
- Working with hospitals to achieve universal birth-dose coverage and documentation of the birth dose in an immunization information system.

Like the reality faced by the AVHPCs, the current level of federal funding for perinatal/HBV programs cannot support these and other core public health services to an appropriate scale that will adequately prevent transmission of HBV from an infected mother to her newborn, provide treatment to the infected mother, and provide screening and vaccine to a mother's sexual and household contacts. It is estimated that 1,000 babies are unnecessarily infected with HBV at birth in the U.S.

Health Department Perspective on Preventing HBV and HCV Infections

State and local health departments are the foundation of the public health infrastructure in the U.S. Unfortunately, due to lack of federal leadership, inadequate funding, and restrictive policies, the expertise of public health programs in responding to the viral hepatitis epidemics has not been fully utilized. Currently, there are no federal funds appropriated specifically for HBV/HCV screening, counseling, testing, and referral; adult HAV/HBV vaccination; acute or chronic viral hepatitis surveillance; HBV or HCV case investigation; HBV or HCV partner services; general public or targeted education and prevention for at risk populations; or viral hepatitis training for the public health workforce. As stated earlier, federal funding to health departments only covers one position that is responsible for coordination of all adult viral hepatitis prevention efforts in a jurisdiction. Due to the inadequacy of this funding, individuals at risk for and living with HBV and HCV are not reached by current public health and health care systems. Additionally, CDC treats hepatitis outbreaks as sentinel events rather than systematically addressing the HBV and HCV epidemics. The urgency of responding to these outbreaks falls to already under funded state and local health departments. Working together, CDC and the state and local health departments respond to these outbreaks, the largest of which occurred in Las Vegas, with an estimated 40,000 individuals potentially exposed to HBV, HCV and HIV. While these activities are central to the role of public health and an important component of viral hepatitis control, they are not prevention, nor a cost effective approach to addressing the likely burden of disease in the U.S.

Even when additional funding has been made available through redirection of existing resources, it is targeted to a limited set of activities. As an example, in FY2007 through FY2010, health departments received HAV/HBV vaccine for adult immunization, but they did not receive funds to support necessary infrastructure, which has proven to be a major barrier to implementation. Health departments and front line providers are grateful to have access to the vaccine, but their efforts to increase vaccine coverage among vulnerable populations are hampered by not having sufficient human or financial resources to implement robust vaccination initiatives. Further undermining adult HAV/HBV vaccination efforts is the uncertainty of continued availability of vaccine. Current efforts have been the result of cost savings from the section 317 immunization program but are not guaranteed to continue from year to year.

Further complicating health department efforts to provide viral hepatitis services, federal funding for adult and perinatal/ HBV prevention efforts come from different CDC divisions and are often granted to different sections of health departments, thus limiting natural coordination between these areas. Similarly, the CDC response to viral hepatitis is shared across two different centers, the National Center for HIV, STD, Viral Hepatitis, and TB Prevention (NCHHSTP) and the National Center for Immunization and Respiratory Diseases (NCIRD). To support the work of health department viral hepatitis programs, opportunities to collaborate and coordinate efforts to prevent and control viral hepatitis must be strengthened at all levels.

Restrictions on the use of federal funding from other public health programs, like HIV/ AIDS and STD, prevent optimal collaboration and integration of services for at-risk clients. By supporting flexibility of federal funding and encouraging program collaboration and service integration, the federal government can increase the efficiency with which health departments and community based organizations deliver important services and can reduce the occurrence of missed opportunities.

In addition, there are effective prevention strategies – like needle and syringe access programs – that are insufficiently funded that are another tool in preventing HBV and HCV transmission. While the evidence base that needle exchange alone reduces HBV and HCV transmission needs strengthening, other activities and services provided by needle and syringe access programs can help to educate those at risk for infection about methods to reduce the harm associated with injection, including possible HBV and HCV infection. Given the high prevalence of HBV and HCV among persons who inject drugs, this important public health intervention deserves increased support and further integration of viral hepatitis services such as HBV and HCV counseling and testing and HAV/ HBV vaccination.

Unlike HIV prevention, health departments do not have a body of research related to behavioral interventions that target populations at risk for acquiring/ transmitting HBV and HCV. With the exception of HAV and HBV vaccines, there are few biomedical

interventions that work to prevent the transmission of viral hepatitis. Research must continue and be funded to support the development of behavioral and biomedical interventions, including an HCV vaccine.

Health departments and community based organizations are uniquely positioned to provide culturally competent prevention services for populations disproportionately impacted by HBV and HCV. Wherever possible, viral hepatitis prevention efforts must acknowledge and strive to eliminate the disparities that exist between those with power and privilege in our society and marginalized populations, particularly those disproportionately impacted by HBV and HCV, including African-Americans, Latino/as, Asians and Pacific Islanders (API), Native Hawaiians, American Indians, and Alaska Natives. Further, viral hepatitis prevention efforts must be initiated and/or scaled up to meet the needs of those who bear the greatest HBV and HCV burden in the U.S. such as African Americans, API, persons who inject drugs, and gay/bisexual men and HIV infected persons in order to provide the coverage of services necessary to reduce behaviors associated with HBV and HCV transmission.

Health Department Perspective on Data/Surveillance to Guide and Evaluate Prevention Services

As is abundantly clear, the resources devoted to the prevention and control of chronic viral hepatitis in the U.S. are woefully inadequate. A hallmark of good public health practice is monitoring the existence, morbidity and mortality of disease. Currently, the CDC DVH funds only seven jurisdictions to support limited surveillance through the CDC Emerging Infections Program (EIP). This project is supported with approximately \$1 million annually. No other jurisdictions receive federal funding to support acute or chronic viral hepatitis surveillance. Most jurisdictions have passive surveillance systems and are quickly overwhelmed by the volume of laboratory reports they receive. Some jurisdictions attempt to conduct active surveillance projects and case investigations, but are limited due to lack of funding and personnel.

To provide contrast, CDC, through congressional appropriations, provides approximately \$67 million to health departments for HIV/AIDS surveillance activities. The data collected and analyzed by HIV/AIDS surveillance programs is critical to targeting the delivery of HIV prevention and care and treatment services. States conduct a variety of surveillance activities to track the HIV/AIDS epidemic including core surveillance, HIV incidence surveillance, national HIV behavioral surveillance, morbidity monitoring, and enhanced perinatal surveillance.

While HIV/AIDS surveillance programs have experienced funding cuts in recent years and need additional funding to provide the best public health outcomes, it is unacceptable that the HBV and HCV epidemics, impacting four to five times as many people as HIV/AIDS, have virtually no public health surveillance. It would be unconscionable if the U.S. attempted to mount a public health response to HIV/AIDS

using data from a system as limited as NHANES. If resources become available for viral hepatitis surveillance, state health agencies are uniquely positioned to conduct these activities because of the expertise, statutory authority, and confidentiality protections of existing public health disease surveillance and reporting systems, like those for HIV/AIDS.

Health Department Perspective on Reducing Morbidity and Mortality

HBV and HCV are treatable – in fact, HCV is curable. Yet, despite staggering numbers of chronically infected people and projections of a dramatic increase in morbidity and mortality from viral hepatitis, there is no dedicated funding stream for chronic disease management of HBV and HCV. Access to care, treatment, and support services is critical for preventing morbidity and mortality from viral hepatitis and for preventing new infections by reducing the pool of infectious persons. While not all infected individuals require treatment, they do need access to primary health care so they are educated about self-care and can be monitored for disease progression.

There is no dedicated funding stream for medical management and treatment of HBV and HCV. While some low-income patients can and do seek services at community health centers (CHCs), not all CHCs have the capacity or expertise to provide care and treatment to persons infected with chronic viral hepatitis. More funding is needed for care and treatment of chronic viral hepatitis, including funding for training and technical assistance initiatives for providers at CHCs to encourage the provision of viral hepatitis prevention, case management, and treatment services for thousands of persons at risk for and living with viral hepatitis.

Most low-income HIV-positive individuals co-infected with HBV or HCV can obtain viral hepatitis care and treatment services through the Ryan White Program, but coverage for HBV and HCV treatment and viral load testing, which is crucial for diagnosis and monitoring response to treatment, is limited. Unfortunately, coverage for diagnostics, monitoring, treatment, and vaccination against viral hepatitis are also not uniformly covered by state AIDS Drug Assistance Programs (ADAPs), due to funding shortfalls. Increased resources for the Ryan White Program are needed for viral hepatitis vaccination, testing, care, treatment, case management, and support services for patients undergoing hepatitis treatment, as well as to improve provider education on HBV and HCV medical management and treatment.

While all health departments do not provide primary or specialty medical care, they are an important part of the process of linking infected individuals to high quality care through referral networks. Unfortunately, there has been very little guidance and no funding from the federal government to support health departments in accomplishing this important role.

As there is no federal funding for HBV or HCV screening, counseling, testing, and referral programs or chronic viral hepatitis surveillance, it is difficult for health departments to assess or assist in linking newly identified cases to care. As a comparison, well established HIV/AIDS surveillance systems collect and analyze data on the number of individuals living with HIV/AIDS and detailed demographic data on individuals receiving services through federally funded HIV/AIDS prevention and care programs. This data is then reported to the federal government in the aggregate to inform its overall HIV prevention and care strategies.

Addressing the Needs of Special Populations

Arguably one of the biggest public health challenges in the U.S. is addressing health disparities that exist for racial and ethnic groups and marginalized populations, such as persons who inject drugs, incarcerated persons, immigrants and gay/bisexual men. HBV and HCV are not the only health issues impacting these groups, but viral hepatitis has not garnered the governmental response in the same way issues such as HIV/AIDS, obesity and diabetes have related to these populations.

Asian and Pacific Islander Americans bear the greatest burden of HBV in the U.S. It is estimated that ten percent of API in the U.S. are chronically infected with HBV. Of the 24,000 HBV-infected women who give birth every year, half are Asian Americans. African Americans and immigrants from sub-Saharan Africa also bear a disproportionate burden of viral hepatitis. Infection with HCV is two to three times as prevalent among African Americans as it is whites. All immigrants from Sub-Saharan Africa are recommended to be screened for HBV due to high endemicity. Latino Americans and immigrants from Latin countries are also disproportionately impacted by viral hepatitis. Studies suggest that Latinos experience more aggressive chronic HCV infections and have a higher risk of developing cirrhosis. Additionally, while there have been tremendous gains in treatment outcomes for whites living with chronic HCV, African Americans and Latinos have not experienced the same levels of treatment success.

Persons who inject drugs bear the greatest burden of chronic HCV in the U.S. In some communities, nearly ninety percent of persons who inject drugs are infected. Funding and policy barriers such as limited syringe access programs and the lack of comprehensive prevention and care services for persons who inject drugs fuel the high prevalence in this population. Limited HBV and HCV testing and HAV/HBV vaccination programs target this important population, but more must be done. Aggressive outreach programs to decrease barriers to needed services must be funded and implemented.

Gay/bisexual men have historically borne a greater burden of HBV than the general population. With the introduction of the HBV vaccine over twenty-five years ago, we have a powerful prevention tool in our arsenal. Unfortunately many gay/bisexual men

have not benefited from the availability of the HBV vaccine. Studies indicate that of gay/bisexual men visiting STD clinics, nearly one half have not been offered HAV/HBV vaccination, a tremendous missed opportunity. While increased education and technical assistance are an important component of this issue, the lack of vaccines for adults, coupled with the need for funding to support infrastructure, are major obstacles to ensuring missed opportunities are minimized.

Recommendations

The Institute of Medicine (IOM) report [*"Hepatitis and Liver Cancer – A National Strategy for Prevention and Control of Hepatitis B and C"*](#) issued a set of recommendations that if implemented would lead to reductions in new HBV and HCV infections, in medical complications and deaths that result from these infections of the liver, and in total health costs. Health departments stand at the ready to implement a comprehensive prevention and control response to HBV and HCV in the U.S. As the institutions that hold leadership over HBV and HCV prevention efforts in states, territories and cities across the nation and as the stewards of one third of the CDC DVH \$19.3 million domestic viral hepatitis prevention budget, health departments recommend (recommendations consistent with IOM recommendations are noted):

- Increase federal funding to support viral hepatitis services, including:
 - National HBV and HCV screening, counseling, testing, and referral. (*IOM Recommendation*)
 - Meaningful implementation of national HBV and HCV testing guidelines.
 - Infrastructure to maximize the reach of adult vaccination programs. (*IOM Recommendation*)
 - National acute and chronic viral hepatitis surveillance systems in all 50 states, the District of Columbia, large cities, and the U.S. territories. (*IOM Recommendation*)
 - HIV surveillance systems to support monitoring of HIV and HBV/HCV coinfection.
 - Public health workforce training on viral hepatitis prevention and control. (*IOM Recommendation*)
 - Medical care and treatment to uninsured or underinsured people with chronic HBV or HCV. (*IOM Recommendation*)
- Target prevention efforts towards populations most impacted by HBV and HCV, including API, African Americans, immigrants from high endemic countries, Latinos, persons who inject drugs, and gay/bisexual men and HIV infected persons.
 - Develop and diffuse effective behavioral and biomedical interventions for populations at-risk for being infected with viral hepatitis. (*IOM Recommendation*)
- Expand programs to reduce the risk of HBV and HCV infection through injection drug use by providing comprehensive prevention programs. At a minimum, the programs should include access to sterile syringes and drug preparation equipment. (*IOM Recommendation*)

- Support collaboration and integration between HBV and HCV services, as well as between HBV, HCV, and other areas of public health within health departments.
 - Create funding announcements and supportive services that promote collaboration and integration between viral hepatitis programs and allied public health programs particularly HIV/AIDS, STD, immunization, refugee health, substance use prevention and treatment, Ryan White programs, and community health centers.
 - Integrate viral hepatitis prevention messages and core public health services in HIV/STD partner services.
- Appoint an individual in the Department of Health and Human Services (HHS) tasked with coordinating the intra-agency response to viral hepatitis.
- The HHS Office of Minority health must provide leadership in addressing the disproportionate burden of HBV and HCV among API, African Americans, Latinos, and Native Americans.

We welcome the opportunity to work with you on this important issue. It is essential that the United States continue to demonstrate its commitment and leadership in fighting the hepatitis epidemics and resources are made available to meet its growing needs. The National Alliance of State and Territorial AIDS Directors thanks the Chairman, Ranking Member and Members of the Committee for their thoughtful consideration of our recommendations.