

Written Statement of

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As Executive Director of the Hepatitis Education Project and a Steering Committee Member of the National Viral Hepatitis Roundtable, I respectfully submit testimony for the record for the hearing “Viral Hepatitis: The Secret Epidemic” and in response to the Institute of Medicine’s recent report, *Hepatitis and Liver Cancer: A National Strategy for Prevention and Control of Hepatitis B and C*.

Since 2001, I have had the privilege of managing the Hepatitis Education Project (HEP), a national nonprofit organization based in Seattle, Washington dedicated to improving the lives of those affected by hepatitis. HEP works with populations most affected by viral hepatitis and often least connected to the health care system. Our partners include local, state and federal agencies as well as other community-based organizations.

In this testimony, I will address the urgency of the hepatitis B and hepatitis C epidemics; the role of community-based organizations in addressing this crisis; and my personal experience.

Two Viruses, One Crisis

The urgency of the public health threat posed by hepatitis B and hepatitis C to our country cannot be overstated. More than 5 million Americans are living with chronic viral hepatitis, or almost 2 percent of the U.S. population.

Most of those living with hepatitis B or hepatitis C are unaware of their infection and often remain asymptomatic for decades. Those who remain undiagnosed can unwittingly transmit the viruses to others and unknowingly do things to exacerbate their own liver damage. Many will be diagnosed only when their liver is failing. Sadly, thirty percent or more will eventually develop cirrhosis of the liver and some of those will die from end-stage liver disease. Others will die from liver cancer.

Much of the disease burden from viral hepatitis is preventable. Hepatitis B is preventable through a simple series of vaccinations. For those who are already living with chronic viral hepatitis, the prognosis is usually very good when diagnosis is made early. Hepatitis B and hepatitis C are treatable conditions; and hepatitis C is often curable. For people to be treated for hepatitis, however, they have to be diagnosed. This remains one of our greatest challenges.

Viral hepatitis in the U.S. must also be viewed through the lens of health disparities. Hepatitis B disproportionately affects Asian Americans and Pacific Islanders (API) at rates more than twenty times that of their non-API counterparts. A staggering 1 in 10 foreign-born APIs has chronic hepatitis B. For new hepatitis B infections, there are racial, behavioral and geographic disparities. African American men and injection drug users have the highest rates of those newly infected with hepatitis B; and southern states have a disproportionate number of those new infections.

Hepatitis C disproportionately affects African Americans and Hispanics. And the majority of new hepatitis C infections occur in injection drug users. The real ticking

time-bomb, though, is the prevalence of chronic hepatitis C among baby boomers, those born between 1946 -1964. It is estimated that 2-3 million boomers are currently living with hepatitis C. Most of these men and women were infected more than 30 years ago; the overwhelming majority remains unaware of their status. For the fortunate minority who get diagnosed, many will already have advanced liver disease that is more difficult to treat and manage and leads to progressively worsening and costly health outcomes such as end-stage liver disease and liver cancer. These outcomes are preventable but not if we maintain the current programs, policies and levels of funding for prevention.

Addressing the Epidemics – the Role of Community-Based Organizations

Community-based organizations like the Hepatitis Education Project do much of the work related to viral hepatitis prevention, testing, education and referral to medical care. Programs at my agency include hepatitis A and B vaccination; hepatitis C antibody testing; a national support hotline; education programs for at-risk youth, prisoners, public health workers and medical providers. HEP also operates one of the few walk-in resource centers for hepatitis patients in the country.

Unlike many other disease states, there is very little federal support for these efforts. In FY2010, for example, the Division of Viral Hepatitis (DVH) at the Centers for Disease Control and Prevention (CDC) received \$19.3 million. By way of comparison, the budget for domestic HIV prevention for the same period was more than \$600 million.

Of the \$19.3 budget CDC allocated in FY 2010, about \$5 million went to states and some city health departments, or about \$90,000 for each state and each of five cities. This is a woefully inadequate amount to address epidemics that affect more than 5 million people – less than \$1 per patient per year.

As a result of this inadequate government response, organizations like the Hepatitis Education Project are vaccinating more people against hepatitis A and B, and testing more people for hepatitis C than any public health district in our state. We are proud of the work we do, but the efforts of community-based organizations like ours should complement, not substitute, the work of governmental and public health agencies.

I am hopeful that this hearing and the IOM report will help to outline and stimulate an appropriate governmental response to these twin epidemics and provide the rationale needed to increase funding for critical programs and services.

Two Viruses, One Family

Until very recently I was a hepatitis patient, an experience that is often fraught with uncertainty. When I was diagnosed with hepatitis C relatively little was known about the virus.

Hepatitis C was only discovered in 1989, and from the early through the late 90's this new epidemic was often compared to HIV except that it attacked the liver, not the

immune system. Through the mid-90's, reports about hepatitis C grew increasingly dire. People with hepatitis C were dying from their disease. Some people were lucky enough to get a liver transplant, but that was thought to just delay the inevitable.

I sought medical care for my hepatitis C in 2000. By then, the medical community had a better understanding of the natural history of the disease, but there was still much that they did not know. In 2002, I had a liver biopsy which showed that I had some liver damage, but not enough to warrant immediate treatment. I had the kind of hepatitis C that responded to treatment about 50% of the time. With newer, more effective treatments thought to be commercially available within 5 years I decided to wait for the next class of drugs and in the meantime monitor the health of my liver. Five years came and went and so did the expected due date for the next class of drugs. Now, I was looking at 2010 at the earliest. I had my second liver biopsy in 2007 and the results were not what I wanted to hear. My liver damage was progressing and if I didn't do something, it was likely that I would progress to cirrhosis relatively soon. Once I had progressed to cirrhosis, there would be other potential complications.

In January, 2009, I was very fortunate to enter a clinical trial looking at a promising experimental new drug to treat hepatitis C. The virus rapidly became undetectable in my body and I completed treatment in December, 2009. Just last month I received my final lab results and learned that I am cured. I happily use the past tense now when I say that I *was* a hepatitis patient.

I talk about my hepatitis story because it the story I know best. It is not, however, the story that is most important to me – that would be the story of my wife, Lily, and our little boy, Sacha. Shortly after I met Lily, I told her that I had hepatitis C and explained to her what that meant and how it was transmitted. Later I explained that there was another epidemic that was equally invisible to the general public – hepatitis B. I knew that among the groups at greatest risk were people born in countries where hepatitis B is endemic. One of those countries is China – where Lily was born. I asked Lily if she had ever been tested for hepatitis B and she said she didn't know. I suggested that it would be a good idea to find out her status. She didn't seem to think it was that important. After some cajoling - and close to another year - Lily was tested for hepatitis B. The results showed that she had chronic hepatitis B, likely contracted at birth from her mother. Fortunately it was inactive, the doctor said, but as she gets older she would need to be monitored regularly and checked for early signs of liver cancer. She took the news almost as stoically as she had when I suggested she get tested in the first place.

Confronting the Crisis – A Time for Leadership

I would like to end this testimony on a note of optimism. There are gaping holes in this country's response to viral hepatitis – that's why we're here. There are, however, examples of successful, life-saving initiatives we can look to for inspiration. Since the early 90's there has been a recommendation in the U.S. that all pregnant women get tested for hepatitis B, and all babies born to hepatitis B positive mothers be given a series of protective vaccinations beginning within 12 hours of birth. A pregnant woman with

hepatitis B will transmit the virus to her newborn about 90% of the time. However, if the newborn gets this series of shots, including the hepatitis B vaccine, the child will almost always develop immunity and not develop chronic hepatitis B. As a result of this initiative, we have seen new hepatitis B infections contracted in the U.S. plummet. Also, as a result of this initiative, my little boy was given life-saving vaccinations that spared him the potential fate of dying young from complications related to chronic hepatitis B.

I am encouraged by recent events that show a growing awareness of this public health crisis. Promising developments include the IOM report on Viral Hepatitis and Liver Cancer, the introduction last year of the Viral Hepatitis and Liver Cancer Control and Prevention Act (HR 3794) and the new Interagency Workgroup on Viral Hepatitis headed by Asst. Secretary of Health Koh.

We have an opportunity and we have a responsibility to use this momentum and act now. It should be a collaborative effort – government, industry, payors, health care providers, advocates and patients – but government needs to lead. We need strong leadership within the U.S. government to coordinate a comprehensive response that uses the information we have now, seeks to collect additional information on best practices and effective interventions and implements nationwide programs that include and build upon the core elements of public health to provide information, services and referral into quality care for everyone at risk for, and infected with, hepatitis B and hepatitis C. If we wait, hundreds of thousands of Americans will die unnecessarily premature deaths. If we act now, we can save many of those lives.