

## 2008 Dean's Scholar Research Proposal

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I hereby waive my right to access the faculty recommendation letter.

Amanda Wong 2/20/08

## **Abstract**

Hepatitis B (HBV) infects a staggering 130 million people in China alone and 400 million worldwide, making it 10 times more prevalent than HIV and 1000 times more prevalent in those of Asian descent than in Caucasians. Worldwide, 1 in 10 Asians are chronically infected with HBV, but in many regions of rural China, the rate is as high as 1 in 6. Unfortunately, chronic carriers in Asia must face not only the physical consequences of their disease, but also the social: those found to be HBV positive are denied jobs, education, and housing. As is the case with many sensitive issues, discrimination is widespread and general, extending to all people and situations linked to hepatitis B. For this reason, HBV awareness and education is of paramount importance. I plan to research 1) the role that hepatitis B plays in access to higher education and 2) the level of awareness regarding HBV transmission, prevention, and treatment among the general public, medical students, and doctors. This latter focus will be an extension of my current 2-year study (at Cornell) on level of HBV knowledge on the Cornell, Duke, and University of California Berkeley campuses. Preliminary results have shown a general confusion of hepatitis B with the non-lethal, more common hepatitis A and a lack of knowledge regarding transmission, across all three campuses. In China, where the disease is much more common but also much more feared, I expect a higher level of awareness accompanied by more misconceptions. The goal of this project is a publication elucidating the current HBV 'climate' in Beijing, China, and recommendations for better awareness and prevention efforts.

## **About the Author**

I am currently a third-year English major with a concentration in East Asian Studies and plans to pursue medical school after graduation—a strange combination of interests that has resulted from my work with the nonprofit sector of minority health education.

I originally hail from Cupertino, California, home to Apple Computers and a large Asian population. In high school, I attended a conference hosted by the Asian Liver Center at Stanford University regarding minority health issues and, in particular, the hepatitis B epidemic. The concept of differing health issues for different ethnicities fascinated me, and I became hooked on medicine. In retrospect, that was when I also became hooked on the Asian Liver Center (ALC), a small yet influential nonprofit organization dedicated to raising awareness of hepatitis B and liver cancer among the Asian population. For the next four years of high school, I was a member of their Jade Ribbon Youth Council (jade for hepatitis B awareness). We did everything from passing out brochures on the street to soliciting political support for increased minority health awareness in public education. Despite the ALC's many international projects, they were rather absent on the East Coast, and I was unable to continue working with them when I arrived at Cornell.

My first two years of college saw me as a biology major, rather narrow-mindedly bent on securing that pre-medical education. During the summers, I continued to work as an intern with the ALC and the American Cancer Society, organizing health conferences for high school students, hepatitis B patients, and Traditional Chinese Medicine practitioners to further spread awareness of HBV. But there's something about waking

up each morning and knowing that you would probably go out, talk to someone, and make a profound difference in their lives. I missed that at college, even with all the community service and student organizations available. In 2006, a friend and I founded the Team HBV chapters at Cornell and Duke. We spread awareness at our schools and surrounding communities through general outreach, game tournaments, guest lectures, and movie nights. We also run an ongoing study about HBV awareness on our campuses, among populations that should be most aware of this issue, but which are currently not. It is a testament to how widespread and unaddressed this issue is, that within two years, Team HBV chapters have also been established at UC Berkeley, UC Davis, Harvard College, Columbia Medical, and Pittsburgh Medical, with more requests coming in every month.

My daily contact with people and bureaucracy, trying to fight against ignorance and apathy, changed my outlook on education—I wanted to use it, not just receive it. I became an English major, fulfilling a long-term interest of mine and also helping me to hone a skill I had come to realize was absolutely essential: the ability to communicate. The decision to come to Beijing was also a result of this desire.

Here in Beijing, I am a student at the Peking University Medical School (also called the Health Science Center), taking courses in social research strategies, Traditional Chinese Medicine, Chinese language, and Chinese culture. In my one week here, I have noticed that hepatitis B is an extremely sensitive issue, and have already met several students who have faced or known someone who has faced the effects of this stigma, despite statements from the Ministry of Health regarding anti-discrimination policies. Researching this stigma and how to fight it will be difficult, but I believe that the consequences of not doing anything justify this research all the more.

## **Statement of Purpose**

### *Background*

Almost daily, reports of new health issues and epidemics arise, from SARS to the avian flu to increased HIV counts. But rarely do we hear about another epidemic, 10 times more prevalent than HIV and 100 times more virulent: hepatitis B<sup>1</sup>. Even in China, where the number of infected individuals is as high as 1 in 10, media advertisements are much more likely to concern HIV and other STDs than hepatitis B (HBV)<sup>2</sup>. This is a result of a widespread stigma against those with hepatitis B, largely regarded as a dirty disease. HBV carriers in Asia face discrimination in every aspect of their lives, from childhood playmates to access to higher education to health insurance to job hunting. At the root of this discrimination is a lack of awareness about a disease that, in day-to-day life, is much less readily transmitted than a cold.

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<sup>1</sup> Asian Liver Center at Stanford University, Physician's Guide to Hepatitis B. 2007. Stanford, CA

<sup>2</sup> World Health Organization. Hepatitis B fact sheet [on the Internet]. 2000 Oct [cited 2008 Feb 18]. Available from: <http://www.who.int/mediacentre/factsheets/fs204/en/>

Hepatitis B affects 400 million people worldwide, and China carries the greatest burden of the disease, with a documented 130 million people infected<sup>1</sup>. It lists hepatitis B among its top three causes of death by cancer<sup>2</sup>. In a world where a safe and effective vaccine has been available for over 25 years, this is unacceptable. Because over half of all liver cancer cases worldwide are caused by hepatitis B, the WHO has dubbed the HBV vaccine the first anti-cancer vaccine<sup>3</sup>. Although there is no cure for chronic HBV infection, treatment and monitoring are relatively inexpensive and hassle-free. Unfortunately, the virus is generally asymptomatic, earning it the name of the “silent killer”--most who are infected do not feel it until the late stages of cirrhosis or liver cancer<sup>1</sup>. Most Asians are chronically infected at birth, from infected mother to child, and as a result of the usual 20-30 year viral incubation period, most also develop liver failure in the prime of their lives<sup>4</sup>. But if a child born to an infected mother is vaccinated within the first 24 hours of birth, the infant is protected from infection in 90% of cases<sup>1</sup>. Like other STDs, HBV can only be transmitted through the mixing of contaminated blood or body fluids, and not via shared utensils, sneezing, or kissing. Prevention and eradication of this disease is very feasible, and with the help of awareness efforts, effective treatments can also be made widely available.

In China, one of the major obstacles to effective treatment of the disease is discrimination. A study by the China Foundation for Hepatitis B Prevention and Control (CFHPC) reveals that 77% of foreign-owned companies will not hire those with hepatitis B, citing fear of infection among employees<sup>5</sup>. Although most of these companies have an anti-discriminatory policy, it is not enforced in their Chinese branches: blood tests are a common part of the interview process, and if waived, many employers will contact health insurance companies directly to verify an applicant’s HBV status.

Discrimination is also prevalent in the education system. Last year, highly publicized case involves 19 students in the Xinjiang Uygur Region who were discovered to be hepatitis B positive and made to leave secondary school despite having received

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<sup>3</sup> Parkin DM. The global health burden of infection-associated cancers in the year 2002. *Int J Cancer*. 2006;118:3030-44.

<sup>4</sup> Beasley RP, Hwang LY, Lin CC, Chien CS. Hepatocellular carcinoma and hepatitis B virus: a prospective study of 22,707 men in Taiwan. *Lancet*. 1981;2:1129-33.

<sup>5</sup>“ Nearly 80 percent foreign companies won.” *China Daily* 28 Jun 2007 [cited 18 Feb 2008]<[http://www.chinadaily.com.cn/bizchina/2007-06/28/content\\_5421170.htm](http://www.chinadaily.com.cn/bizchina/2007-06/28/content_5421170.htm)>.

governmental scholarships to attend<sup>6,7</sup>. Seven of them sued their schools for discrimination, prompting a nationwide outcry and an anti-discrimination warning by the Chinese Ministry of Health. However, the statement contains no legal ramifications or lifting of compulsory testing, and several of the students have not been reinstated.

This sort of discrimination occurs even among universities in large cities such as Beijing. All institutions of higher education require a health report before final acceptance. Peking University and Tsinghua University, the two most prestigious universities in the nation, have a standing policy for those found to be hepatitis B positive: they are deferred admission for one year, during which they must determine whether or not their HBV is actively transmittable and provide proof of being 'cured'. For those whose infection is discovered after admission, the policy is the same. Upon return one year later, they are required to repeat their previous year. Those with hepatitis B are completely denied access to Chinese medical schools, even for study in non-invasive vocations.

Although there are different subtypes of the virus, one cannot say that one is more transmittable than the other, or that someone can have active or non-active HBV. All carriers are equally likely to transmit the disease, which can be transmitted only through sex, contaminated needles, or wound-to-wound contact. The fear that the virus is contagious in casual daily activities is largely unfounded. Dispelling discrimination at this level is particularly important: these students are the future leaders and employers of China and can heavily influence the continuation (or discontinuation) of this stigma.

A two-year awareness project by the CFHPC in 6 rural Chinese counties resulted in a 63% increase in general HBV knowledge and subsequent 44% increase in newborn vaccination rates, proving that education does have a significant impact on public health<sup>8</sup>. The CFHPC continues to implement awareness projects in various regions of China, though they have not begun a formal study at the university level.

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<sup>6</sup> Qiang, Guo. "Hepatitis B virus carriers shunned in China." China Daily 31 Oct 2006 [cited 18 Feb 2008] <[http://www.chinadaily.com.cn/china/2006-10/31/content\\_721308.htm](http://www.chinadaily.com.cn/china/2006-10/31/content_721308.htm)>.

<sup>7</sup> Chang, Tianle. "Hepatitis B stigma provokes outcry in Xinjiang." China Development Brief 30 Oct 2006 [cited 18 Feb 2008] <<http://www.chinadevelopmentbrief.com/node/840>>.

<sup>8</sup> LIU, Chong-bai, SU Chong-ao, and WANG Cheng-xin. "Analysis on Health Education on Hepatitis B Control and Prevention in Rural Areas in China." Chinese Journal of Vaccines and Immunization R186(2005):

*Aim 1: Researching discrimination against hepatitis B carriers among Beijing institutions of higher learning*

I will research the current official and social attitudes towards hepatitis B carriers in Beijing universities. In the Haidian district alone, there are 22 universities, most of which specialize in a particular field of study; I plan to encompass most if not all of them in this study. Not all universities have the same policies regarding hepatitis B, though a physical examination is required by all. I will look for correlations between stringency of regulations and school specialty or renown. These policies are not always published online, but can be researched in the school libraries and through meetings with school officials. My status as a Peking University (PKU) student should grant me access to most of these resources.

Aside from confirming official university admission policies, I also plan to study the social attitudes of teachers, students, and university employees towards hepatitis B, mainly through the use of surveys and personal interviews. Surveys will be distributed within the dorms where access is possible, or otherwise outside of lectures. If possible, I will also set up an online survey to increase accessibility.

My mentor at the PKU Public Health Department, Ph.D candidate Lu Cong, is experienced in researching the healthcare policies in both cities and rural areas and has promised to assist me in this project.

*Aim 2: Evaluating methods and effectiveness of HBV awareness*

My research will focus on the effectiveness of HBV education techniques currently employed by NGOs such as the China Foundation for Hepatitis B Prevention and Control (CFHPC). The CFHPC Program Manager, Linda Zhang, has promised me the opportunity to participate in their current Beijing awareness projects and studies. Either in conjunction with them or on my own, I plan to evaluate awareness of HBV on university campuses on the same surveys for part 1 of my project. As in all social research, quantitative data can be hard to obtain or be inconclusive; I will also conduct oral investigations of student awareness levels, especially at the medical schools.

I plan to do this with the assistance of existing HBV activist student groups at Peking and Tsinghua Universities. Students Yang Aimin and Zhang Xiaopeng are

leaders of the Sunshine Volunteers organization and have led projects to raise funds for HBV vaccination and awareness in rural areas of China. With their help, I hope to be able to assess current awareness levels among the student population, implement awareness projects, and evaluate the effectiveness of these projects based on increase of HBV knowledge.

To increase the sample size, I will begin this project within the next month and continue it during the summer, after the Cornell semester ends.

Ultimately, I plan to sum up this research in a paper describing the current HBV climate in Beijing, along with recommendations for better HBV awareness techniques and emphasis on any key misconceptions. I also plan to, with permission, compile any and all extensive oral interviews into a written depiction of life for HBV carriers in Beijing. This will be the springboard for my planned senior thesis in Creative Writing.

Although this research may not make a splash (more like a ripple) in the current social attitude towards HBV, I do hope that it is a ripple that will touch off other movements, taking us one step further in eradicating HBV discrimination and HBV itself.

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