

## DOUBLE STIGMA

Living with HIV and No Green Card in Chinatown

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Every morning around seven, Susan Lee<sup>□</sup> rises from the bed she rents for \$200 a month in a shared apartment and gets ready to go to work. Her shoulder-length brown hair is highlighted with two broad orange streaks which conceal her forty-seven years and hint at her profession, which is cutting hair in a Chinatown salon. On this chilly winter day, she draws dark blue eyeliner on her lower eyelids, bundles up with four layers of sweaters and a black leather jacket, and makes her way through the cramped Chinatown streets, already alive with produce sellers and shoppers alike. She blends into the milling crowds, just another employee on her way to work.

Chinatowns in any city are the best places to live if you have a secret, and New York is no exception. Asian-American activists often reject Chinatown's reputation as a bastion of secrecy and underworld transactions, but to some extent the characterization is deserved. Chinatown is a place beyond the reach of the law, but not because the people don't understand American laws. They simply aren't afraid of them. It's a place where people keep their heads down and their mouths shut, where parents tell their children that the nail that sticks out gets hammered down, and people say that even if someone was shot in the middle of a crowded street, the cops would never know who did it. Blending in is a survival tactic that capitalizes on the inability of non-Asians to distinguish one Asian face from another. So it's no surprise that Lee has a secret. In fact, she has a few. She is an undocumented immigrant who is living with HIV.

Drawn to the United States by the availability of AIDS treatment, undocumented Asian immigrants living with this disease are caught in a tight intersection, a place where the politics of health care and immigration collide. Like the estimated seven million other undocumented immigrants in the U.S., they face the daily obstacles of finding a job and a place to live, while sending money to their families back home and staying off the police's radar screen. But they must also get special medical treatment without telling anyone else in the Asian community, where AIDS continues to carry a strong stigma, despite the increasing prevalence of the disease.

The group has been largely ignored by the AIDS community, the Asian-American community, and the immigrant rights community. This is partially because they choose to remain silent, but also due to the double stigma of being undocumented and living with HIV/AIDS (this story will generally refer to the disease as AIDS). Then again, there just aren't many of them. According to the city's Department of Health, 927 Asian Pacific Islanders (APIs) had AIDS in New York City in 2003, comprising a mere one percent of infected people city-wide.

Although the furor that AIDS first created has died down, the epidemic is far from over in the U.S. In fact, the face of the disease has changed considerably. When AIDS arrived in America in 1981, and throughout the next decade, its face was upper-middle class, gay, white, and male. Today, the disease latches onto those who are poor, nonwhite, and disenfranchised. Far from an

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<sup>□</sup> Some names have been changed to protect the privacy of individuals with HIV/AIDS.

indiscriminate disease that could affect anyone at anytime, it has proved to be selective towards the vulnerable and ignored, spreading fastest among susceptible populations such as young African-American women in the U.S., monogamous married women in India, and rural farmers in southern China. In the next generation, AIDS will be associated with urban centers and people of color. “It will be unfathomable as a white gay disease,” Kang says.

All signs point to Asia as the next frontier of the epidemic. An estimated seven million people in Asia are living with AIDS, and some experts predict that in 2010, Asia will have more AIDS-infected people than the almost 22 million in sub-Saharan Africa today (the U.S. has 950,000). Combine the growing epidemic in Asia with the recent wave of immigration from the region to New York City — Asia has accounted for one-quarter of the immigration to NYC since the early 1990s — and it’s clear that this subculture is a ticking timebomb.

However, the non-white, non-gay, non-male face of AIDS has always been invisible among activists, and it remains in the fringes today. In February 2005, the prevailing stereotype surfaced once again and got the attention of the New York City media when a promiscuous gay man was found to have a particularly drug-resistant strain of HIV that escalated to a rapid onset of AIDS. (He is believed to have had sex with hundreds of men in the months leading up to his diagnosis.) Confronted with this sensational news, city and state health authorities promised more outreach to gay communities, especially users of methamphetamines. They also pledged to focus on younger gay men who take a cavalier approach to unprotected sex. But there was no mention of outreach to immigrants, lower-class minorities, or women, the populations that arguably need prevention, education and services the most. Minority AIDS programs have been long underfunded, and the Ryan White Comprehensive AIDS Resources Emergency Act (CARE), which provides services to communities of color and the poor, is up for renewal this year. Funding for the Ryan White CARE Act has remained flat at about \$2 million for the last three years, according to a 2004 report from the Kaiser Family Foundation, and activists across the country are calling for President George W. Bush to take a stand in the fight against AIDS in marginalized communities by increasing CARE Act funding.

The first step towards focusing policymakers’ attention on the diverse face of the AIDS community is perhaps the most difficult. Lacking the visible and vocal presence of the gay community, undocumented immigrants face greater risks in calling attention to their AIDS status and medical needs. It requires people like Lee to risk being deported and risk losing life-extending AIDS treatments, her job and perhaps her housing. “Silence equals death” was the powerful rallying cry used by AIDS activists to illustrate the Reagan administration’s refusal to acknowledge AIDS in the 1980s, and it still rings true today for Asian immigrants and other disenfranchised cultures who are struggling with this terminal and stigmatizing disease.

### **The Quest to Be A Good Mother**

As a hairdresser in Malaysia with only a sixth-grade education, Lee dreamed of joining her two younger sisters in New York, both of whom came to the U.S. twenty years ago on tourist visas and eventually obtained green cards. She made almost no money in Malaysia and hoped to make a fortune in the U.S., or at least enough to send home to support her two young sons. She had already been rejected for a visa twice when she heard rumors of another way to get into the

country. In 1999, she paid a Malaysian travel agency that specialized in such journeys the equivalent of \$2,000 to arrange the entire trip. Her journey included a one-day stop in Korea, a lone flight to Toronto where she pretended to be visiting relatives, and a boat trip from Canada that smuggled her and five or six other Chinese migrants into the U.S.

Besides her sisters, the rest of her family remains in Malaysia, including her two sons, who were three and five years old when she left. Today they are ten and twelve, and though she talks to them often, she would not recognize them now, because she has not seen them for so many years. She divorced her husband, an unemployed gambler who didn't take care of the family, when the youngest son was a few months old. Her mother has been taking care of the children since she left, and every month Lee sends home \$400 — half her monthly salary — to pay for the boys' school fees and living expenses. "That's a lot in Malaysia," she says.

In January 2004, Lee developed a terrible cough that persisted for two weeks. "I never felt that way before," she recalls during an interview in Chinatown, speaking to a translator and a reporter in her native Cantonese. Her relatives took her to the hospital, where she stayed for another two weeks while doctors ran tests and studied x-rays of her lungs. When she failed to recover after two weeks, her doctor asked for permission to give her an HIV test. At the time, she had heard of AIDS, but didn't know what it was or how it was transmitted. Back home in Malaysia, she didn't know anyone with the disease. But she agreed, assuming that if the doctor suggested the test, there must be good reason to take it. Lee was diagnosed with HIV near the beginning of the Chinese New Year. She was shocked by the news.

The timing of the diagnosis was especially poignant because the New Year is traditionally the happiest season of the year, and a time to celebrate surrounded by family. Here in New York, Lee lives alone. Although she lived with her sisters for three years when she first came to the U.S., now both sisters have their own families and there's not enough space. Her feelings about her children are excruciatingly strong, even though they are thousands of miles apart and she has her own troubles in the U.S. Her biggest fear is not that she will die alone in a foreign country, or that she will be deported. Instead she fears that she might not send enough for her sons to complete high school. She had originally hoped to go back after getting a green card, but she has abandoned that plan. "I don't stand a chance for a green card now. I miss them, but there's nothing I can do because I can't go back," she says before breaking into tears.