

TREAT ASIA REPORT

Fighting AIDS From the Heart

The *TREAT Asia Report* Interview: Michelle Yeoh



Michelle Yeoh is recognized internationally for her work as a film star, action heroine, and humanitarian. Acclaimed for her portrayals of strong female characters and for performing her own stunts in such films as Crouching Tiger, Hidden Dragon, she has long been involved with Asian and global charities, among them amfAR, The Foundation for AIDS Research, for which she serves as an ambassador.

Yeoh was born in Malaysia of ethnic Chinese parents and is now based in Hong Kong.

TREAT Asia Report: You've been involved in the fight against AIDS for many years. What convinced you that this issue needed your support?

Michelle Yeoh: I strongly believe in the need to work on behalf of this cause. For women, protecting themselves from HIV/AIDS is a fundamental issue and one that convinced me to speak out publicly. I remember when I was first approached to take a public stand against HIV/AIDS—some advised me not to become involved with an issue that was connected with sex and acts that some people felt were shameful. But I was convinced that ignorance and fear can sometimes be more contagious and dangerous than the disease itself.

CONTINUED ON PAGE 8

AIDS Care China

Model Partnership Provides Red Ribbon AIDS Care

In mid-2007, the five HIV/AIDS specialists at China's Longtan Hospital were treating nearly 1,000 HIV patients, many of whom had difficulty coming in for follow-up visits or to pick up medications. Overwhelmed by the demands of providing medical care, doctors and nurses found themselves unable to closely track their patients' adherence to treatment or ensure that they received counseling and social support.

During the past two years, however, Longtan Hospital has seen a decrease in the number of patients lost

AIDS Care China's founder Thomas Cai (center) with clients from a Red Ribbon Center in Hubei Province. (Photo: Karl Grobl)



CONTINUED ON PAGE 6

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TREAT Asia is a network of clinics, hospitals, and research institutions working with civil society to ensure the safe and effective delivery of HIV/AIDS treatments throughout Asia and the Pacific.

The information in the *TREAT Asia Report* is compiled from a variety of sources and may contain controversial views and opinions not endorsed by amfAR. Material in the *Report* should not be used as the basis for medical diagnosis or treatment.

This newsletter is also online at www.treatasia.org.

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Collaborating on HIV/AIDS in China



Since TREAT Asia's earliest years, we have worked closely with a range of partners in China, collaborating on HIV observational research, treatment literacy, community development, and research capacity-building. This issue of the *TREAT Asia Report* focuses on how far these efforts have come, and reminds us of the challenges of caring for the estimated 700,000 people living with HIV in China today.

We start with an interview with amfAR Ambassador Michelle Yeoh (*page 1*), who has used her celebrity status to shine a light on the needs of people living with HIV in China and around the world.

Her efforts have led to greater support for programs like the Red Ribbon Centers (*page 1*), established by AIDS Care China with technical and financial support from TREAT Asia and GlaxoSmithKline-Positive Action. These centers help improve medical management and provide social support for people with HIV/AIDS, among them members of a family whose story appears on *page 7*.

Chinese researchers have made significant advances in understanding the path of the epidemic by studying treatment outcomes for adults and children on antiretroviral treatment. But recent publications indicate that many obstacles remain to improving and scaling up treatment access, and that local acceptance of people living with HIV can be problematic (*pages 4 and 5*).

Facing and fighting stigma and discrimination is a common thread that runs through this issue of the *TA Report*. China's advocates, scientists, and program implementers are promoting greater understanding of how HIV affects us all. We look forward to continuing our work in China and to supporting the efforts of our Chinese partners.

Annette Sohn, M.D.
Director, TREAT Asia

TREAT Asia Focuses on MSM and Community Advocacy at ICAAP

Reaching vulnerable populations and involving affected communities in the implementation of HIV services were two of the major issues addressed by TREAT Asia and amfAR representatives at the ninth International Congress on AIDS in Asia and the Pacific (ICAAP), held in August in Bali.

At a pre-conference meeting on HIV among men who have sex with men (MSM), amfAR CEO Kevin Robert Frost presented

a new amfAR report calling for a robust research effort to help understand the most effective models for HIV prevention, treatment, care, and support among MSM in Asia and the Pacific. The report, *Ensuring Universal Access to Comprehensive HIV Services for MSM in Asia and the Pacific*, warns that if HIV prevention does not improve, "MSM will soon account for the

CONTINUED ON PAGE 7

Pulling Together to Combat Treatment Failure

TREAT Asia Convenes Think Tank on Preventing Treatment Failure

Treatment failure among people living with HIV in Asia is associated with a variety of factors, including a lack of clear, up-to-date treatment information for patients, variations in drug potency or quality, and poor adherence to first-line regimens. Treatment failure is compounded in many countries by limited access to second-line therapy options and to laboratory monitoring tests that can correctly identify treatment failure.

In an effort to address these obstacles and develop ways to share the latest research on drug resistance and treatment options with affected communities, TREAT Asia convened a think tank in Bangkok in August as part of a pilot project to bring together scientists, patients, community educators, and advocates around the issue of treatment failure.

As participants shared personal and professional experiences with treatment failure, identified knowledge gaps, and proposed next steps, a growing sense emerged that current approaches to treatment literacy, and the impact of literacy on delaying treatment failure, need to be reexamined. Community treatment educators noted that there are few educational tools to help patients understand the connection between poor adherence and drug resistance. Participants also felt that people living with HIV need better access to treatment experts who could provide reliable advice about treatment changes, side effects, or laboratory results when physicians are not available.

Think tank attendees also discussed the need for more research on drug resistance in Asia and the importance of increased access to advanced laboratory testing. While the benefits of research studies and clinical trials tend to be limited to higher-income countries, such research can nonetheless provide important scientific evidence for improving patient management throughout Asia and increased access

important in improving adherence, detecting treatment failure, and improving the chance that patients will respond to subsequent regimens.”

One of the most frustrating obstacles for advocates working to promote understanding of treatment failure and prevent drug resistance is the limited treatment options available to patients. There has been a growing global outcry over the lack of access to affordable

second-line regimens—a problem that must be addressed as more patients experience resistance to first-line drugs.

“Treatment failure and the lack of an adequate response will leave many people living with HIV in a desperate situation,” said Paul Cawthorne of Médecins Sans Frontières. “If this meeting strengthens the links between clinicians, scientists, academics, and affected communities, we may have better hope for the future.”

Participants concluded that community advocates, clinicians, and researchers must

work together to promote better monitoring and access to treatment. As the coordinating center of the only regional program monitoring HIV drug resistance in Asia, TREAT Asia is uniquely placed to bring these stakeholders together to increase understanding of treatment failure, promote expansion of antiretroviral treatment options, and advocate for the inclusion of viral load testing in treatment services. ■

to new antiretroviral drugs and funding for lab monitoring. Participants observed that despite the increasing number of studies showing that CD4 count alone is a poor predictor of treatment failure, viral load monitoring continues to be difficult to access and is seldom paid for by national HIV programs.

“By not monitoring patients with viral load, we are giving substandard care,” said Dr. Jintanat Ananworanich of HIV-NAT and the Thai Red Cross AIDS Research Centre. “Viral load is



Think tank participants (L to R): Yuitiang Durier, Siriraj Hospital; Jennifer Ho, TREAT Asia; Wasana Prasitsuebsai, Siriraj Hospital; Paul Cawthorne, MSF; Jintanat Ananworanich, HIV-NAT/Thai Red Cross; Thida Singtoroj, TREAT Asia; Addy Chen, APN+; Pathompong (Tom) Serkpookiaw, APN+.

Combining Antiretroviral and Anti-Tuberculosis Treatment Reduces Risk of Death

More than half of all tuberculosis cases worldwide in 2009 were in Asia.¹ The three countries with the highest disease burden were India with two million cases, China with 1.3 million, and Indonesia with more than half a million.

People who have both HIV and tuberculosis are at much higher risk of death than those with either infection alone, and up to half of all HIV patients may die during tuberculosis treatment. However, starting tuberculosis treatment too soon after beginning antiretroviral treatment (ART) can lead to even higher risk of death due to complex interactions between the body's immune system and the tuberculosis bacteria.

In order to better understand what factors reduced the risk of death, researchers in Thailand studied patients with both HIV and tuberculosis.² Their study included 667 patients with

tuberculosis and HIV from 32 government-supported hospitals. More than half (58 percent) of the patients had tuberculosis only in the lungs, about a third (31 percent) had tuberculosis in other places in their bodies, and the rest had disease in

Waiting too long or not starting ART at all can lead to much higher risk of death.

multiple places, including the lungs. The median CD4 cell count was 60 cells/mm³; 80 percent of patients were below the WHO-recommended treatment threshold (<200 cells/mm³). However, only 41 percent of patients received ART during their tuberculosis treatment. Those who

started ART for the first time generally delayed ART for two months (median 62 days).

A total of 112 patients (17 percent) died after their tuberculosis diagnosis. Being on ART during tuberculosis treatment was associated with an 84 percent reduction of the risk of death. The use of co-trimoxazole or fluconazole to prevent opportunistic infections was also found to be beneficial.

Researchers are still working to determine the best time to start ART during tuberculosis treatment, but this study shows that waiting too long or not starting ART at all can lead to much higher risk of death. ■

¹ WHO. *Global Tuberculosis Control 2009: Epidemiology, Strategy, Financing*. 2009; Geneva: WHO.

² Varma JK, et al. HIV care and treatment factors associated with improved survival during tuberculosis treatment in Thailand: An observational study. *BMC Infectious Diseases* 2009, volume 9: article 42 (available for free at www.biomedcentral.com/1471-2334/9/42).

Social Support and Psychosocial Distress Among Children Affected by AIDS in China



An HIV-positive child in China. (Photo: Karl Grob)

An estimated 100,000 children orphaned by AIDS are believed to be living in China. However, research on the psychosocial well-being and the social support needs of these children has been limited. A recent study was conducted to examine the relationship between social support and psychosocial well-being of children (aged 6–18) living in Henan, China, a rural province where large numbers of people became infected with HIV after exposure to contaminated blood products in the late 1980s to mid-1990s.¹

Surveys were completed by 404 children who had not experienced HIV-

Antiretroviral Treatment Outcomes in China

An estimated 700,000 people are living with HIV in China. By August 2008, more than 52,000 had started antiretroviral treatment (ART) through the Chinese government's free program.

A recent evaluation of the program's first five years reported on treatment outcomes for 48,785 ART-naïve, adult patients who were started on triple-drug combinations.¹ More than half (53 percent) were infected through contaminated blood products and 82 percent were living in rural areas. Their baseline CD4 count before starting ART was a median of 118 cells/mm³. Almost all patients (91 percent) received nevirapine (NVP) in combination with zidovudine (AZT) or stavudine (d4T), and didanosine (ddI) or lamivudine (3TC).

The study showed that deaths were highest in the first three months of ART, occurring in five percent of all patients. Mortality rapidly dropped by six months of ART, and at five years 76 percent of patients were alive. Patients were more likely to die if they had lower CD4 cell counts and more clinical symptoms of HIV disease before starting ART.

In a subset of 31,070 patients who had more detailed laboratory information, one-fourth failed treatment based on their CD4 cell counts over the five-year period. Half of all patients who had reached the five-year point failed treatment.

related illness or death in their families, 466 children living with HIV-infected parents, and 755 orphans who had lost one or both of their parents to HIV. None of the children had HIV themselves. The survey contained questions about emotional support from family, friends, and teachers, as well as questions about psychosocial aspects of life, such as loneliness, self-esteem, and perceived control over the future.

The researchers found that children who felt they had higher levels of social support also reported lower levels of depression and loneliness and higher levels of self-esteem, perceived control over their futures, social skills, and interest in attending school. Older children, orphans, and girls reported feeling higher levels of social support than other children. While higher levels of family support were reported

A treatment education session in Hubei Province, China. (Photo: Karl Grobl)

The results of China's national program show that scale-up of ART was achieved across a wide geographic region in largely rural areas and that early mortality was quickly reduced within six months. Starting patients on ART at higher CD4 cell counts and before advanced clinical disease could lead to even lower early mortality rates.

Although the risk of treatment failure was very high, the failures were identified through CD4 cell count alone and not viral load. As CD4 by itself has been shown to be a poor predictor of treatment failure, it is likely that these are overestimates. Unreliable diagnoses of treatment failure could lead to unnecessary treatment switches, leaving people with HIV with fewer antiretroviral options in the future and higher costs to programs for second-line drugs. ■

¹ Zhang F, et al. Five-year outcomes of the China National Free Antiretroviral Treatment Program. *Annals of Internal Medicine* 2009, volume 151, pages 241-251.



by orphans who had lost one parent compared to children who had lost both parents, the study showed similar levels of psychosocial problems between the two groups.

Notably, children whose HIV-infected parents were still alive reported lower levels of social support. Possible reasons for this include fewer government-sponsored programs for non-orphans, the stress of having chronically ill caregivers, and the stigma associated with having HIV-positive parents.

This study emphasizes the importance of social support programs for children affected by HIV. These programs can have a significant impact on reducing mental and emotional stress in the lives of these children and improving their hope for a stable future. ■

¹ Hong, Y. et al. Perceived social support and psychosocial distress among children affected by AIDS in China. *Community Mental Health Journal*, 17 June 2009. (Epub ahead of print)



A patient counseling session at the Xiangfan Red Ribbon Center. (Photo: Karl Grob)

to follow-up and a significant improvement in patient health—thanks in large part to the work of AIDS Care China, a TREAT Asia-supported organization whose Red Ribbon Centers are now functioning at 28 hospitals and clinics in south and central China.

Founded in 2001 by HIV-positive advocate Thomas Cai, AIDS Care China is considered a model for community-based HIV care in the region. “AIDS Care China promotes the concept that people living with HIV/AIDS should not isolate themselves in a small circle of fear to be pitied,” said Cai.

The Red Ribbon Centers provide support services for people living with HIV including counseling and education on antiretroviral treatment (ART) and opportunistic infections, social support, and financial assistance for transportation and other expenses. They also help doctors and nurses focus exclusively on medical care by taking on essential administrative tasks such as patient appointments and follow-up, maintaining confidential patient information, and ensuring that patients have consistent and adequate supplies of medication.

“The biggest benefit of having the Red Ribbon Center here is having people who help us monitor the patients, and ensure that they come to pick up their medicines,” said Dr. Meng Zhihao, inpatient director at Longtan Hospital.

TREAT Asia has supported AIDS Care China since 2005, providing funding for the establishment of four Red Ribbon Centers and technical assistance in training staff and developing treatment literacy materials. To evaluate the centers’ impact on patients’ treatment adherence, overall health, and well-being, TREAT Asia recently developed a case study of three of the centers, including the one at Longtan Hospital. The

results showed that in addition to improved adherence, all three centers reported increases in patient CD4 levels that persisted over time. At the Xiangfan and Nanzhang hospitals, where viral load testing is available, the number of patients with no detectable viral load increased markedly, with more than 90 percent of clients at the Xiangfan center achieving an undetectable viral load. And patients reported that the social support they received at the centers gave them a sense of hope for the future.

The key to the Red Ribbon Centers’ success has been their integration into local government healthcare systems, creating a platform for collaboration between medical personnel, government officials, and people living with HIV. Staff at the centers have worked to develop close relationships with doctors and nurses—who in turn have grown to rely on the centers as key sources of patient-care support. These collaborations have also led to changes in local and provincial government policies.

“We work very closely with the Red Ribbon Center staff,” said Ye Hengbo, deputy director of the health bureau in the city of Xiangfan. “As soon as the patients pick up their medicine, they must go to the Red Ribbon Center to receive information and counseling.”

A personalized approach to counseling and education has helped keep Red Ribbon Centers connected to the communities they serve; many of their trained counselors are themselves HIV positive. Patients attend one-on-one counseling sessions before and after medical visits and receive treatment education in small group discussions.

“HIV patients really need more care and support, and communication and counseling, than other patients,” said Dr. Lee Rong, director of the outpatient department at Longtan Hospital. “Our time as doctors is limited, and when we are off work, the Red Ribbon Center is still here, providing support.”

To help rural patients with the cost of traveling to cities for appointments and medications, AIDS Care China has set up a transportation fund. The Red Ribbon Centers also operate a short-term shelter service.

One patient from Longtan described her experience at a Red Ribbon Center shelter when she and her 18-month-old son were first diagnosed. “The staff at the shelter really helped a lot. They constantly explained to me about the situation and why I should get my son on treatment. There was another positive child there—a nine-year-old orphan—and one of the staff there was positive and had a daughter who was positive. So I felt my son could survive. I decided to take him for treatment, and now he is doing very well.” ■

Learning to Hope in Kunming

Xiao Yue (whose name has been changed to protect her privacy) discovered she was infected with HIV when her husband was hospitalized with complications from HIV. When he died, she and her young son—both of whom had been infected as well—faced life on their own. For the past two years they have been receiving antiretroviral therapy at the Yunnan HIV/AIDS Care Center in Kunming, the capital city of Yunnan Province in China.

I first learned that I was HIV-positive when my husband was hospitalized for more than a month with cryptococcal meningitis. The doctor said his situation was too complicated to treat so I brought him home and later he died. But his HIV status became public knowledge where I lived, and I was forced to take my child and move away.

Even though I was HIV-positive, at that point my CD4 count was still

high. So I decided to live without thinking about treatment. Before I was diagnosed I had no knowledge of HIV and no related information—nobody had told me anything about it. After I was diagnosed, I became very afraid of getting sick and being discriminated against. It is not an easy task to deal with this on your own.

“ Before I was diagnosed I had no knowledge of HIV—nobody had told me anything. ”

Looking for support, I told a family member of my husband’s and she accepted me, but she still couldn’t understand why we got HIV. I also told my own family, and they gave me much support. But after my son and I started treatment, I found the most help from my peers at a group activity organized

by the Red Ribbon Center. Some of the HIV doctors helped us a lot, too. The Red Ribbon Center staff has explained the facts about HIV and I’ve learned what I need to do for our treatment to be successful. This knowledge really helps me to face the truth and live with confidence.

My son is now six years old and

his experience at school and with friends has been a good one—he gets along well with other classmates. But we never tell anyone at school about his status. He’s so young that it makes

me sad, but I dream that there will be a cure for HIV. If not, I hope we’ll be able to remain on treatment. I want to be able to bring up my son, and I’d like to remarry. And I also really like to help other people with HIV by doing volunteer work in my community ■

(Interview conducted by Li Yun)

ICAAP CONTINUED FROM PAGE 2

largest proportion of people living with HIV in Asia.” It outlines an agenda for operations research that could guide organizations and governments in developing an effective range of programs that could be incorporated in national AIDS strategies and donor initiatives.

At the conference, TREAT Asia’s MSM program coordinator Hua Boonyapisomparn gave a plenary presentation on the need for collaboration between health systems and the communities they serve. She offered examples of successful programs in India, Thailand, and China for which TREAT Asia provides technical support, and used her own experiences as a

transgender person to illustrate the need for community involvement.

“Without community advocates who can identify and address these gaps in care for transgender people, our voices will not be heard and our health needs will not be met,” she said. “We need to invest in the community as much as we need to pay for medicines and blood testing.”

In addition, TREAT Asia community program manager Jennifer Ho presented a poster on the involvement of people living with HIV in the work of AIDS Care China, a TREAT Asia-supported organization that provides treatment education and support services. (See story on page 1.) ■

TA Report: From your perspective, what are the most pressing issues facing Chinese communities, in China and across Asia, when it comes to confronting HIV/AIDS and supporting people living with HIV?

Yeoh: Stigma and discrimination are two of the biggest problems. Families and communities are the heart of Chinese life, but so many times I've seen the stigma of HIV/AIDS break those bonds—discrimination by relatives, neighbors rejecting long-time friends.

One of the most heartbreaking things I've seen in my work on HIV is the stigma HIV-positive children often face in their communities. When people refuse to let their children play with HIV-positive children, or prevent them from attending public school, then it's time for all of us to speak out.

Access to treatment is also critical. China is making a strong effort to provide greater access to treatment, but there are many migrant workers from China and other countries who have difficulty accessing free HIV care and medicines.

It is also important to provide social support for people living with HIV. HIV can take a serious toll on so many aspects of life. Children who have lost parents to HIV/AIDS or whose parents are ill may need help with education fees. Some people with HIV may be unable to work and must rely on others to help provide for their basic needs. Providing social services can make a significant difference in people's daily lives.

TA Report: As you mentioned, discrimination and stigma against those living with HIV are widespread. In your experience, what are the most effective ways to address the lack of knowledge that underpins fear and stigma?

Yeoh: Perhaps because I have lived my life in the public eye, I believe that one of the most powerful ways to combat stigma

is to speak out publicly about AIDS. A lot of people don't know the basic facts about prevention, testing, how the virus is transmitted, and why they shouldn't be afraid of someone with HIV. If we bring the subject out into the open, I hope that people will eventually realize that HIV should not be a mark of shame.



Michelle Yeoh at an amfAR fundraiser, 2008 (Photo: Getty Images/Pascal Le Segretain)

China's political and economic leaders have acknowledged the impact of HIV on Chinese society and have taken a public stand. The government is committed to expanding treatment and some politicians have openly embraced people with HIV/AIDS. China's leaders see the epidemic as a human and social development challenge, rather than a moral issue.

Without leadership, it is difficult for a country to make real progress against the stigma associated with HIV/AIDS. We need leadership to combat the discrimination that makes it hard for people to seek treatment if they become infected, hold a job, sustain relationships, and live active lives in their own communities.

TA Report: How important is it for a public figure like yourself to speak out about AIDS?

Yeoh: The media is the quickest and most powerful way to speak out. Those of us who have the attention of the media are privileged, and we have the responsibility to put that privilege to good use! I am fortunate because I can draw public attention to HIV/AIDS and help people understand that this is a disease that can be stopped. This work cannot slow until we have defeated the epidemic on every front around the world. ■



New Research in Translation

To help disseminate topical new research conducted in Asia and around the world, TREAT Asia is now providing translations of selected research stories into a variety of Asian languages, among them Burmese, Chinese, Khmer, Thai, and Vietnamese. Available as PDFs at www.TREATAsia.org, in the AIDS Research Information for Asia section, the translated articles have been selected for their relevance to HIV/AIDS communities across the region.