

China: Thousands of Children Face Barriers to AIDS Treatment

(Bangkok, April 20, 2009) — Thousands of HIV-positive children in China may not be receiving the treatment and care they need, Asia Catalyst said today. Based on interviews with children, families and frontline AIDS workers in rural China, Asia Catalyst’s new report documents the obstacles to treatment faced by children, and urges China to expand its existing programs.

The report, “I Will Fight to My Last Breath: Barriers to AIDS Treatment for Children in China,” documents how HIV-infected children in China face serious economic and social barriers to getting government-supported help to which they are legally entitled. These barriers range from gaps in the government treatment program that impoverished families cannot afford to fill, to the refusal by some hospitals to treat children with AIDS.

“China has made great progress in the fight against AIDS, but far too many children are getting the wrong AIDS treatment,” said Sara Davis, executive director of Asia Catalyst. “Indeed, thousands may not be receiving any treatment at all.”

The report draws on research in Beijing and in Yunnan Province, the southwestern province with the highest official HIV prevalence rate in China.

Children living with HIV need pediatric treatment. The Clinton Foundation's HIV/AIDS Initiative helps the Chinese government obtain and distribute these medicines to families for free. However, many children have developed resistance to the first line of AIDS medications, and second-line treatment is not included in the government program. Regulations of the World Trade Organization (WTO) allow countries to issue “compulsory licenses” to manufacture urgently-needed medications. In the past, the U.S. has penalized countries, such as Thailand, that issue compulsory licenses.

“People are dying of AIDS because they can’t afford second-line treatment, but China currently has the capacity to make these medicines,” said Davis. “China should be supported and encouraged to do so.”

Asia Catalyst urged the Chinese government to immediately issue compulsory licenses so that the urgently-needed second-line AIDS drugs can be produced, and said the Obama administration should end the Bush-era policy of punishing countries that issue compulsory licenses.

The Chinese government’s AIDS program, known as “Four Free, One Care,” does not pay for treatment for opportunistic infections for many children. Even where the proper antiretroviral treatments are freely available, other costs remain, such as laboratory fees,

equipment, treatments for opportunistic infections, and transportation costs.

“‘Free treatment’ is not always truly free. We spoke to families that had to sell their homes, their businesses, their possessions, all to care for their children -- and they still didn’t have enough money,” Davis said. “One of the children we interviewed died a few months later when his family could no longer pay for his care.”

The report also documents a lack of properly-trained doctors, and hospitals that turn away children with HIV/AIDS out of fear of contagion. For some families in hard-hit rural areas, local hospitals are unreachable. Some families interviewed were completely unaware that free AIDS treatment programs even existed.

While China’s leaders have urged compassion for people with AIDS, discrimination and stigma remain widespread. Schools sometimes refuse children who are HIV-positive, who may also be rejected by their extended families and by other children.

The responsibilities overwhelm some families, and a few even abandon their children because they cannot face the challenges of caring for a child with HIV/AIDS.

“It’s a heavy burden for a child to grow up with HIV/AIDS in China, and it’s a heavy burden for their families as well,” Davis said.

Asia Catalyst’s report is being released simultaneously in English and in Chinese at the International Harm Reduction Association conference in Bangkok, Thailand.

To launch the report, Asia Catalyst will hold a panel discussion at NYU Law School on April 28, featuring Prof. Jerome Cohen (NYU Law School), Prof. Joanne Csete (Columbia University), a speaker from UNICEF, and the report authors. The panel discussion will run from 6:30 p.m. to 8:00 p.m., followed by a reception. Details are available at www.asiacatalyst.org.

A web campaign at www.asiacatalyst.org/pediatric_AIDS_report showcases photographs from the research trip, and a sign-on petition calling on the U.S. to endorse compulsory licensing of AIDS treatment. Donations to the campaign will go to a Chinese NGO that provides AIDS treatment to children.

Asia Catalyst, a nonprofit organization based in New York City, partners with activists in Asia to inspire, create and launch innovative, self-sustaining programs and organizations that advance human rights, social justice and environmental protection. For more information, visit www.asiacatalyst.org.

Quotes from “I Will Fight to My Last Breath”:

“My mother and father have always given me faith. They tell me not to look down on myself. They say that I should fight to my last breath, and that they will treat my illness until their last penny is gone.” – a fourteen-year-old who died of HIV/AIDS when his

parents ran out of money to treat him

“I am in pain in every inch of my body. There is not a single part of me that feels okay.”
– a child with HIV/AIDS describing side effects she experiences from taking adult medications

“ARV drugs are already ineffective...and many people are already resistant to the first-line drug treatment...so for many people the situation is not very optimistic.” – an AIDS worker in Henan

“We haven’t (tested) our child. We don’t want to take him to get tested. We’re afraid that after the test... we wouldn’t have the capability to take him to see a doctor. We don’t know how to receive the support.”- a woman living with HIV in Yunnan

“Some people are utterly unable to bring their children to the hospital [because of the cost]. They try to buy some of the medicines themselves, or do whatever they can on their own, and their children just die.” – a HIV-positive mother in Yunnan

“In the non-infectious disease hospitals, they will tell people ‘go away! We don’t want you here, go to another hospital.”-- Director of an AIDS NGO in Yunnan

“Before I had this sickness, it wasn’t that my family had a lot of money, but we were about middle class. Now we are in debt everywhere...[and] it’s very bad and shameful to have to borrow money. We don’t have anything except for a place to live.” – a HIV-positive child in Henan

“[His family] just said they couldn’t care for him anymore.” – a doctor at a Beijing hospital, describing an HIV-positive teenager whose parents abandoned him on the road by the hospital.

“I can’t go to school. All the students in the school are afraid of me, and from the beginning they would not play with me. The teacher told me the school doesn’t want me to attend.” – a HIV-positive child from Henan