XVI International AIDS Conference:

The Response to HIV/AIDS in India

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Ladies and Gentlemen:

It is an honor to address this distinguished audience and represent my country India on this global platform. India, with an estimated 1.1 billion people this year, has a population that is amongst the most diverse in the world, where the rich and poor alike enjoy a strong cultural identity and heritage.

This year marks exactly two decades since the first case of AIDS in India was reported in Chennai, Tamil Nadu. Since then, the situation has rapidly escalated into a national pandemic that has exceeded our worst predictions. So many lives of both my country's men and women have been lost, children have been orphaned, and poverty and hunger have been exacerbated. India, along with the rest of the world, has been fundamentally changed by HIV/AIDS.

The national response to the AIDS epidemic in India is a collaborative and synergized effort of the government, private organizations, pharmaceutical industry, international donors and NGOs and individuals. Following the identification of HIV positive individuals in 1986, the Government of India established NACO, the National AIDS Control Organization. NACO implemented the National AIDS Control Programme (NACP), which has made steady progress over the years. Today, HIV/AIDS has been placed on the national political agenda, where an institutional framework for the national response has been established, levels of awareness have been increased, blood safety has been improved, and the tracking of the epidemic has been strengthened.

With the completion of the second phase of the National AIDS Control Programme this March, the implementation of the third phase will begin this November. During this phase it has been projected that India will spend $2.5 billion within the next five years to fight the HIV/AIDS pandemic. Teams of the World Bank and other international organizations are planning to contribute to this phase. This phase aims to prevent new infections by covering high-risk

groups like commercial sex workers, truck drivers, drug users and men having sex with men with “targeted interventions”. However, the focus can no longer be solely on high-risk population as the HIV/AIDS epidemic has shifted from the high risk population to bridge populations like clients of commercial sex workers, wives at home and partners of drug users, and to the general population. Therefore, the ‘third phase’ also aims to focus efforts on women, adolescents and children, who are highly vulnerable to HIV infection.

NACO, under the central government of India, has decentralized itself by making AIDS a state subject, where each state of India is now an independent and responsible organization. The key for India now is to tailor innovative intervention models based on the strengths and weaknesses of individual states.

There has been an increase in the government’s own expenditure on HIV/AIDS but the financial resources available to fight HIV in India are far below what is needed. India is responding simultaneously to the extraordinarily complex demands of the HIV/AIDS epidemic and to its other public health problems like tuberculosis, malaria, cardiovascular diseases, and family planning. With so many curable life threatening diseases that we must deal with in India, the fundamental questions remains: why invest everything in a terminal ailment like HIV/AIDS?

By the end of 2005, India had earned the dubious distinction of reporting 5.7 million cases of people living with HIV/AIDS – the highest for any country in the world. A grim and remorseful realization is that these statistics do not accurately represent all the men, women and children, who are known to be infected, in addition to the silent carriers. Research has shown that for every 25 who know that they are HIV positive, 75 are silent carriers.

HIV prevalence in India has been calculated based on the Annual HIV Sentinel Surveillance (HSS) studies conducted across the country. In 2005 there were 750 sentinel surveillance sites around the country, which include STD clinics, antenatal clinics, TB centers, and de-addiction centers. The assumption taken for the estimation of prevalence has been that people attending STD clinics and de-addiction centers practice high risk behavior and would include the population groups of female commercial sex workers (FSW), men who have sex with men (MSM) and intravenous drug users (IDU). Until recently there have been no studies on the community prevalence of HIV available in India. Women attending antenatal clinics have been taken as proxy for the general population as they are not mobile, sexually promiscuous and adventurous. However in rural areas, women give birth at home with the help of midwives called *dais*, and often do not go to clinics or hospitals for antenatal care, deliveries or to be tested for HIV.

In response to this, a first community based survey is being conducted this year to measure the actual HIV/AIDS burden in India. The government believes HIV infected individuals comprise less than 1% of India’s population. Since November of last year until this August, the National Family Health Survey-III has been collecting random blood samples from 29 states, which after being tested will undoubtedly reveal facts that will call into question the validity of prior statistics.

This new community based survey will determine the following: how many men and women are actually HIV positive, whether urban or rural India carries more of the burden, the age group that is most affected and the prevalence of the disease in India's six most affected states - Andhra Pradesh, Karnataka, Tamil Nadu, Maharashtra, Nagaland and Manipur.

India is at crossroads in its efforts to control the HIV/AIDS epidemic. Taking into account the size and density of the nation’s population, even a small increase in infection rates will result in a huge number of new infections. According to a recent report by the Registrar General and Census Commissioner, India is

estimated to lose 16 million lives in the next 20 years due to HIV/AIDS. Moreover, 60% of India's HIV/AIDS population is faced with the co-infection of Tuberculosis and AIDS creating a severe dual-epidemic. A simultaneous infection with these two interrelated catastrophes is almost always an irreversible formula for death.

There is a window of opportunity to contain the HIV/AIDS pandemic, but a multi-pronged approach addressing every aspect of our fight needs to be further strengthened to effectively contain the epidemic and concurrently maximize the life-span for those already infected. This includes further bolstering our commitment, activism, interventions, health care, development of preventative technologies, innovations of new medicines, and increasing financial resources to fully combat this epidemic.

I can definitely say that from our current position, a couple of years ago, there is an initiation towards large-scale changes in our fight against HIV/AIDS. For years, India did not include 'Antiretroviral Drug Therapy' in its AIDS control programme. However, given how quickly the pandemic was spreading in India, three years ago I took it upon myself to convince the Finance Minister that ARV was needed. I said, "Let us not forget that those who are most vulnerable to the devastations of HIV/AIDS are the men, women and children from disadvantaged, underprivileged, and uneducated societies. How can one think about getting tested for HIV when one does not even know what it is? How can one think about seeking treatment for their condition when one cannot even afford to feed himself and his family? Most importantly, when there is no hope for treatment, why would anybody want to know their HIV status?"

The Finance Minister was viably moved and totally convinced of the 'multi-pronged' approach. NACO then worked out the financial costs. Finally, since the year 2004 the government has now commenced the disbursement of first line treatment of ARV for free to people living with HIV/AIDS. This is a great leap

forward in India's response to care and treatment. As of December 2005, the number of people living with HIV/AIDS on ARV is 23,784; out of whom 15240 are men, 7474 are women, 1048 are children and 22 are transgender. ARV centres have been set up in 52 hospitals in 25 states. It is estimated that 10% of the people living with HIV/AIDS are still in need of receiving ARV, therefore substantial augmentation in the numbers receiving treatment is crucial. There is also an urgent need from the international community to create funds for the second line treatment.

Recently, three of India's leading AIDS research institutes have been selected to be part of a prestigious international network, undertaking two separate ground breaking projects to develop and conduct field tests of microbicides to combat HIV. Microbicides, as you know, are active compounds that can be applied inside the vagina or rectum to protect against HIV and offer a potential alternative to condoms. They are seen as an alternative to an AIDS vaccine, which although has enormous potential, will take over 10 years before being readily available. However, even if these microbicides are successful, imagine rural India being able to take advantage of this innovation. I personally cannot imagine many asking, "hand me the tube." We must of course continue to live in hope.

India's pharmaceutical industry has gained global recognition by revolutionizing the cost and accessibility of antiretroviral drugs in developing generic drugs that are currently being used in 90 countries around the world. Our leading pharmaceutical company, Cipla, developed the "triple" ARV cocktail drug, Triomune and offered it to the international community at under a dollar a day. At that time, the price of ARV treatment was at $12,000-$15,000 a year i.e. approximately 35 dollars a day. There was a monopoly on patent holders until the Indian Patent Act was passed in 1973, but since then high-quality generic antiretroviral drugs were made readily available at accessible prices by India's pharmaceutical industry. Unfortunately as of January 2005, the amendment in the Indian Patent Act, which is in compliance with WTO patent laws and TRIPS

(Trade Related Aspects of Intellectual Property Rights), does not permit India's pharmaceuticals to produce generic copies of patented medicines. I appeal to the international community to not follow the dictates of the TRIPS agreement as flexibility needs to be made possible in order to suit the country's need. Let us not deny people's right to life and health in the poorer regions of India, and the rest of the world. As Indira Gandhi, then Prime Minister of India, stated at the WHO Conference in Geneva in 1981, "My idea of a better ordered world is one in which medical discoveries would be free of patents and there would be no profiteering from life or death."

India does have tremendous scientific talent and a wealth of trained health personnel that is an asset to the fight against HIV/AIDS. However, the absence of people specializing in and dedicated to public health is a troublesome gap. In response to this, the newly launched Public Health Foundation of India (PHFI) is intended both to fill this employment gap and to help the country's national and public health leadership find new ways of thinking about the larger Indian response to AIDS pandemic. PHFI is being created by the government, but with direct participation by both private sector and international institutions. It hopes to deliver strong training programs, vibrant partnerships with international institutions, and a major effort to demonstrate the value of public health expertise to the medical establishment.

India's epidemic is unique in many respects, and in order to move strategically forward, it is necessary to tackle the underlying social and public health challenges and integrate a successful balance between prevention and care. State Governments and NGO's all around the country have risen to the challenge and become greatly involved in various areas including the prevention, control and surveillance of HIV/AIDS, public awareness, education, programming, and counseling and care of patients. Many of these NGO's are supported and funded by international organizations.

Our public health care facilities are definitely working towards sensitizing the people they serve, providing them with proper access to information, services and treatment. Health care providers are being empowered with skilled training and accurate information, and are being appropriately regulated and mentioned.

India's response to HIV/AIDS cannot rely solely on medical and healthcare means but must include the social dimension as well. India is still a patriarchal society, with gender prejudice and unequal power in decision-making between men and women. Women are unable to negotiate safer sex, which represent major social obstacles. Imagine a wife ordering her promiscuous and dominant husband to wear a condom. We are also dealing with a large rural population in which many of the men must travel to seek employment in urban India or elsewhere. Sexual promiscuity of these men, which is more culturally acceptable in India, has allowed HIV to cross state borders. Also, an environment of extreme stigma and denial, breeds fear amongst the infected and keeps HIV/AIDS hidden, where it will continuously spread undetected throughout the general population.

As the chairperson of Action India, a citizen's motivated trust working actively in the field of HIV/AIDS, I run a holistic care home Ashraya in New Delhi that provides a continuum of care that is comprehensive and specific to the needs of people living with HIV/AIDS coming from all regions of India. Treatment focuses on areas, such as their medical, psychological and welfare needs. Through the interactions with my patients, I have shared their heartbreak and anguish that this disease brings, not just to those who are directly infected and affected, but to their families too. My patients have lost their jobs, been shunned by their community, faced rampant stigmatization and suffered severe violation of their human rights. I have seen a case of a truck driver who was refused a hip replacement surgery at one of the premier health care institutes in New Delhi because of his HIV positive status. I intervened and ensured that his surgery was performed.

Today, I believe we must join each other and move beyond prejudices and cross barriers to reach out to the millions of men, women and children who are victims of the social and physical degeneration caused by HIV/AIDS so that they are treated with dignity and have access to quality care.