

AIDS IN INDIA

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India's intellectual energy and efficiency are the envy of leaders around the world. Bangalore and Hyderabad have emerged as global centers for innovations in information technology and biotechnology. Multinational companies are racing to take advantage of India's well-educated and low-cost talent to staff call centers and service desks. In the face of such swift development, a less enviable growth statistic is the rapidly escalating HIV/AIDS epidemic. The virus, too, is efficient, spreading silently and perniciously, almost without notice. In 2002 alone, the number of people living with HIV/AIDS increased by more than half a million from 3.97 to 4.58 million.¹ India's billion-strong population masks the prevalence of the epidemic, while in reality India stands only second to South Africa as the country with the greatest number of infections. In South Africa, the epidemic is killing people in their most productive years, eroding decades of development and creating a staggering number of orphans. If left unchecked, AIDS destroys the social fabric and threatens the economic and political stability of a nation.

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Unlike many African nations stricken by the epidemic, India is rich in the technology and resources critical to turning the tide of the epidemic. As a leader in generic drug production, many of the worst affected countries have been turning to India to access low-cost, generic versions of the more expensive, patented HIV medications from the West. In 2001, Indian drug manufacturer, Cipla, was hailed by many developing countries for taking leadership within the international trade regime to provide AIDS medications to programs in developing countries for more than 30% less than the market rate. However, when the head of Cipla, Dr. Yusuf Hamied, initially tried to donate free treatment to the Indian government, his offer was rejected.² U.S. President Bill Clinton recently called on Indian drug companies to solidify ground-breaking price reductions as a mecha-

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nism to secure access to low-cost drugs for governments around the world,³ and international researchers see great potential for India to support AIDS vaccine development.

India is now at a crossroads. Despite technological innovation and good will, India could be the next epicenter of HIV/AIDS. There is one daunting challenge that could undermine the will necessary for success, and that is the need to tackle the stigma and discrimination associated with HIV/AIDS. The stigma allows for India's foundations to reject those living with AIDS and to keep those disempowered at greatest risk. There is a persistent denial and dismissal precluding urgent government action and rapid resource mobilization. Although there is a unique window of opportunity for India to be a prevention success story, it is one that is closing fast. Without a shift, current trends could leave India with 20 to 25 million HIV/AIDS cases by 2010.⁴

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From Sex Workers to Mobile Men with Money

In 1986, the first cases of AIDS in India were detected in Mumbai (Bombay) and Chennai (Madras). Since then, primarily one vector has been associated with the rapid spread of the epidemic across the subcontinent: truckers and the sex workers they frequent at checkpoints and border crossings. Since truck drivers can only cross India's urban centers by night, passing time in transit zones often involves sex with prostitutes. Indian truck drivers have an HIV infection rate that is twenty times that of the national average. In Mumbai, the HIV rate among sex workers is approximately 50%, reaching upwards of 70% in some brothels.⁵

While economic development and entrepreneurship create jobs for truckers, increased wealth and mobility facilitates the spread of the virus. Mobile workers not only have money to pay for sex, but also take the virus back home to their wives and families. In certain villages of Andhra Pradesh, infection rates among pregnant women are greater than 2%, which is more than twice the rate of the national average.⁶ These rates have been increasing steadily since men in these villages have migrated to Hyderabad for work. It is this bridge, facilitating the spread of HIV, between high-risk groups and the general population, between urban and rural, and rich and poor that is cause of great alarm for India's future and for neighboring countries.

Faces of the Indian AIDS Epidemic: Understanding Prevention, Testing and Treatment

A great majority of us must be reminded every day that it is not just the marginalized and poorly educated that are affected by HIV/AIDS. Last year, *India Today* documented the case of Bhupen Yadav, a 27-year-old MBA graduate: "Head hung low, he [Yadav] talks about his heady encounters with a high-society callgirl five years ago. After frequent bouts of undiagnosed fever two years ago, he tested HIV positive."⁷ Yadav indicated he never thought a "guy like him" could get HIV and that it was a poor man's disease. Consequently, as the epidemic spreads, it is important to note that it is no longer a disease that targets only truckers and sex workers, all sectors of society are vulnerable to it.

Concern for long held family values and cultural norms can often override the fear of contracting HIV. In her new documentary, *Pandemic Facing AIDS*, Rory Kennedy captured the story of Nagaraj and Bhanu, a couple from a small rural village in Tamil Nadu.⁸ As documented in the film, Nagaraj was earning well as a trucker until he contracted HIV and became too sick to work. Although Bhanu, his wife, tested negative for the virus, she still was rejected by her family for staying with her HIV-positive husband. Feeling that it was more shameful to remain childless than to risk being infected with HIV, Bhanu tried conceiving a child with Nagaraj. In her pursuit, Bhanu contracted HIV. To help minimize the risk of mother-to-child transmission, her husband gave up his own HIV treatment to help pay for Nevirapine, an anti-HIV medication administered to women during pregnancy.

Geeta Sodhi, Director of Swaasthya, a Delhi-based NGO working to address women's reproductive health needs, acknowledges very frankly that the "mere availability of drugs and awareness is not going to do the job effectively, it is the social fabric that is so weak and disabling that we need to deal with the cultural context. Girls even today have restrictions on their mobility. They get pushed into marriages and cannot seek sex, let alone negotiate condom use. I think we need to pay more attention to the social-cultural context which these individuals face."⁹

The legal context also determines the ways in which people living with HIV/AIDS are affected. On January 16, 2004, AIDS activists hailed a Mumbai High Court ruling that held that government jobs could not be denied to people based whether or not they were infected with HIV alone.¹⁰ In this specific case, a government-owned company denied an HIV-positive woman a permanent job because of her status. The court recognized the company's decision to reject the

woman as irrational and unconstitutional. There have been a series of High Court cases across India that have ruled similarly. Parliament-appointed experts have been working to draft anti-AIDS discrimination legislation that will also prevent against discrimination in the private sector.

One of the greatest challenges in the response to AIDS, in India and worldwide, is encouraging people to get tested for the virus. There is little incentive to learn one's status in the face of harsh stigma and discrimination and the lack of access to life-saving medicines. Clients at Sahara, an HIV care-home in New Delhi established to support drug users, admit that they would not have had the courage to learn their HIV status without the counseling and support of the Sahara community.

Loon, an HIV-positive man working at Sahara and benefiting from antiretroviral drug treatment, feels his case is rare. "I feel bad sometimes taking the medicine because I know so many cannot get it," he notes.¹¹ Prices for drugs have come down in India. Antiretroviral treatment regimens can be purchased for as low as Rs. 1200 (\$27) or for as high as Rs. 10,000 (\$221) per month, depending on the quality. Many of the people who need treatment do not have jobs. Loon emphasized that "treatment is not so simple, it is a lifelong commitment, resistance occurs easily, and there are not many trained doctors who can work with patients and teach them to take their medicines."¹² With so few trained physicians and an annual per-capita health spending as low as three dollars, India's health sector is completely overburdened. HIV/AIDS is competing with a whole host of poverty- and development-related illnesses.

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Expanding the Response: Opportunities for South Asian Americans

While governments can make significant contributions to respond to the health needs of a nation, it is clear that the response to HIV/AIDS requires commitment from all sectors. In countries such as Botswana, Brazil, and Thailand, national responses to the epidemic have resulted from various combinations of high-level political leadership, grassroots efforts, and partnerships with business. South Asian Americans are uniquely positioned to advance ongoing efforts in India on a number of levels.

1. Urge Governments to take rapid action and mobilize resources.

For years, the Chief Minister of Andhra Pradesh, Chandrababu

Naidu, has taken a stand against the epidemic and has been bold in his approach by supporting the placement of giant condoms in the lobby of the State General Assembly and calling for safe-sex dialogues on college campuses. But this type of leadership has been limited. In the past six months, government officials have spoken out against HIV/AIDS and made new commitments, but there has been little action.

In 2003 a variety of advancements took place: Prime Minister Vajpayee called for an immediate response to HIV/AIDS; the Minister of Health, Sushma Swaraj, publicly hugged two HIV-positive children; a first ever national parliamentary forum on AIDS was convened; and the National AIDS Control Organization (NACO) announced a commitment to treat 100,000 people living with AIDS in India. Although NACO and government officials are beginning to take important steps, the government has been heavily criticized for being slow to respond and for not directing interventions to the systemic roots of the epidemic.

Unlike in the past, international donors are now willing to fund HIV/AIDS programs. Between 2000 and 2005, it is estimated that India has been pledged over \$620 million in contributions.¹³ Former U.S. Ambassador to India Robert Blackwell indicated that from 2002 to 2007, the US government would direct \$91.5 million to fight AIDS in India. The US government has supported bilateral responses to address the Indian epidemic, primarily through the U.S. Agency for International Development (USAID), the US Department of Health and Human Services, and the Centers for Disease Control and Prevention. While a significant focus of the government response has been on prevention activities, collaborative research between the US and India on behavior change, mother-to-child transmission, and vaccine development has also been initiated.

The current U.S. Administration has made a significant contribution to fight AIDS globally, calling for \$15 billion over five years for fourteen countries in Africa and the Caribbean. While India, or any Asian nation for that matter, is not included in this plan, there is a provision that allows for the addition of a fifteenth country without geographic restriction.

2. *Engage the business sector.*

On any given day in Jamshedpur, the site of Tata Steel's headquarters in Jarkhand State, one will find three to four HIV activities taking place in the community as part of Tata Steel's response to the epidemic. Ratan N. Tata, Chairman of Tata Sons and Tata Steel, is recognized globally as an advocate against AIDS. Similarly, Delhi-based Modicare is supporting broad-based interventions including

voluntary counseling and testing. Through their testing services, Modicare is finding that close to 6% of their clients are testing positive for HIV, which is almost ten times that of the national prevalence rate.¹⁴ In his personal commitment to the fight against AIDS, company CEO Samir Modi wrote letters to his friends to raise money to cover the treatment costs for people living with AIDS. He is now able to provide seven people with ongoing antiretroviral drugs, but he indicates this is "only seven of hundreds of thousands."¹⁵

Surprisingly, at the September 2003 United Nations General Assembly session in New York it was not the Indian government representatives who spoke out against AIDS, but the Confederation of Indian Industry, India's premier business association. Moreover, although we are beginning to see efforts made by some Indian companies, US-based multinationals have yet to take an aggressive stance against AIDS in India. In fact, many multinational and national companies hail that they have no HIV-positive workers, primarily due to the fact that screening for HIV prior to employment is still legal. Increasingly, US-based companies are relying on the fruits of Indian labor to support the backbone of their operations, but if they do not begin to protect their employees and the communities in which they operate from the epidemic, the consequences could be devastating. Bill Gates committed an enormous amount of resources, \$200 million, to fight AIDS in India, but few have followed his lead.

Richard Holbrooke, former US Ambassador to the United Nations and President and CEO of the Global Business Coalition on HIV/AIDS, urges that "business has too often been an untapped partner. It is an inescapable fact that the sector as a whole has been slow to respond to AIDS. Yet, businesses not only have a responsibility to act, but an opportunity to play a crucial role in the global fight against the epidemic."¹⁶ The American business community has a significant amount of entrepreneurship and innovation they can lend to India's fight against HIV/AIDS beyond financial contributions, whether through supporting the workforce, building partnerships in the community, or implementing broad-based media campaigns to raise awareness and change behavior. Business leaders can also use their influence to urge for greater action. For example, Rajat Gupta, Senior Partner at McKinsey & Co., speaks out regularly against HIV/AIDS and is working to impact the international policy response to the epidemic.

3. Mobilize global voices.

In the past few years we have seen a rise in the number of celebrities willing to associate themselves with the epidemic and push the

barriers in addressing the epidemic. MTV India's top VJ, Cyrus Broacha, uses the media to speak openly about the epidemic. At a recent conference in New Delhi, he expressed: "I think the government as well as the NGOs as well as people like us, we all have to talk to different people and explain to them that sex happens."¹⁷ Cyrus also acknowledges that the barriers are many and that HIV/AIDS "is a problem with families and it is about the support system and the government, only by coming together, then only will the media be effective."¹⁸

In Mumbai on September 18, 2003, the International Cricket Council and the Joint United Nations Program on HIV/AIDS (UNAIDS) entered into a strategic partnership to take up AIDS in cricket playing countries. The Board of Control for Cricket in India (BCCI) will be distributing HIV/AIDS awareness materials to sports commentators and journalists and will invite HIV-positive people to toss the coin before test matches.

Hollywood star Richard Gere is also working intensively to mobilize members of the Bollywood community, sports figures, business leaders, and government leaders around a vocal campaign against HIV/AIDS. When in India, Gere speaks directly with sex workers and their clients about the importance of protecting themselves. "If you work with the creative community, the incredible power of industry, then bring government and the judicial system, you can solve any problem," he noted.¹⁹

HIV leaders in India are calling for more of this type of response. Although often symbolic in nature, these gestures represent the willingness of national heroes to accept HIV/AIDS and to directly tackle the stigma and fear associated with the epidemic.

4. Support community activities.

To date, non-governmental and community-based organizations have carried much of the burden of addressing the needs of those living with HIV/AIDS. After discovering the first cases of HIV/AIDS in Chennai, Dr. Suniti Soloman and her colleagues opened up the YRG Centre for AIDS Research and Education in Chennai, India, which provides care to over 5,000 patients. Activist/Actress, Nafisa Ali, founded Action India, a care-home for HIV-positive patients near Delhi. She expresses her desire to do so much more: "This is a sexual issue in our country, and I really feel for the people in my country. I feel because I am a care giver and I find it a human right violation to find such little support for care and treatment programs."²⁰ Groups such as Action India, YRG, and Sahara are overwhelmed. The experience is universal: there are simply not enough beds, and the hospitals are crippled by poorly main-

tained equipment. Even if medicines were affordable, there still would not be enough trained physicians to administer and monitor the complicated drug regimens required of the medicines to patients.

In the US, a team of physicians has taken initiative to lend their skills and resources to communities in India. Dr. Vishnu Chundi and his colleagues have formed the Metro Foundation to support direct implementation of programs focused on health promotion and disease prevention. The group partners with locally operating NGOs to provide care to communities in and around Hyderabad. Designed to help achieve overall goals of India's government program, they are working to expand their program in partnership with the GATI Corporation, India's largest transport company covering 565 of India's 602 districts, to reach out to over 2,000 truck drivers and transport workers. A native of Andhra Pradesh, Dr. Chundi emphasizes that for any group working to address HIV in India, "treatment challenges must be locally based. Across India, language, values and culture differ from state to state, even between districts, what works in Assam may not be effective in Gujarat or Andhra Pradesh. It is also important to have clear partners operating locally and show evidence-based progress."²¹

The Way Forward

During a satellite conference between the U.S. and India in October 2003, Tarun Das, Director-General of the Confederation of Indian Industry, expressed that dealing with HIV/AIDS "is part of a reform process. We always talk about economic reform but here we are talking about a much deeper social reform. A mindset reform, a behavioral reform, a private life reform. We as a country are conservative and cautious, so it makes it so much more difficult and challenging to address...One of the biggest single uncertainties hovering over India is what it does to address HIV/AIDS. If it turns to a small problem, this is a country that is poised on the brink of really quite extraordinary development. If it doesn't then it will justify the cynics and I would hate to see that happen."²²

South Asian Americans have a critical role to play in this process, and a concerted effort on their part will help India to become part of the global response to the epidemic. There is a unique opportunity to support and enhance India's response by being creative and drawing on shared cultural values and influences.

The South Asian community can take leadership in a number of areas by:

- Leveraging links with Indian Parliamentarians, opinion leaders, and gov-

ernment officials.

- Lobbying the U.S. government to secure further funding. The South Asian community could urge for full AIDS spending and advocate for India to be included as the fifteenth country in the President's new \$15 billion Emergency Plan for AIDS Relief.
- Directing resources, skills, and expertise. Health and development professionals can direct their own resources, skills, and expertise to support ongoing programs, train medical providers, and fill gaps in the current response.
- Organizing events in India, U.S., and Europe to raise awareness about the urgency of HIV/AIDS in India.
- Bringing celebrities, athletes, musicians and other personalities to speak out against AIDS in South Asia and engage in open conversations about how one can protect oneself from HIV.
- Adopting an HIV-positive person in South Asia by supporting his/her care and treatment costs.
- Donating supplies and resources to clinics and care homes treating people living with HIV/AIDS.
- Engaging with umbrella groups such as SAATHII (www.saathii.org) that are working to mobilize and link individuals and community organizations in the U.S. and India.
- Advocating to personal contacts in India to take responsibility for their actions and destigmatize the epidemic.
- Increasing awareness in the South Asian American community.

For India, there is a burning need to be honest about modes of transmission and to explain openly how HIV is transmitted, as well as how it can be prevented. With no vaccine or cure in sight, only a frank assessment and acceptance of what kind of epidemic India is facing and how it should respond will take India in this positive direction. In his address to the National Convention of the Indian Parliamentary Forum on HIV/AIDS in New Delhi, India, in July 2003, Peter Piot, Executive Director of UNAIDS, alerted that "India still has the opportunity to forestall a massive epidemic" and posed delegates with the challenge, "Will India find its future crippled by a massive HIV epidemic, or will India be an example of leadership in action against AIDS in Asia and the whole world?"²³ Governments and donors need to reevaluate their priorities and find innovative ways in which to partner with civil society and business to curb the tide of this devastating epidemic and to preserve decades of development.



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 16. See Global Business Coalition on HIV/AIDS, www.businessfightsaids.org.
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 19. The Associated Press, "Actor Richard Gere Announces Project To Expand Public Discussion of HIV/AIDS in India," December 2, 2003.
 20. Remarks by Nafisa Ali at a Conclave on "Accelerating the Business Response to AIDS: Partnerships and Action," convened by the Confederation of Indian Industry and the Global Business Coalition on HIV/AIDS.
 21. Personal interview with Dr. Chundi from the Metro Foundation, January 2004.
 22. See transcript from "AIDS in Asia: Leadership Initiatives in India," a satellite conference between New Delhi and New York sponsored by the Asia Society and the Confederation of Indian Industry, October 14, 2003. www.kaisernetwork.org.
 23. See Text of speech by Dr. Peter Piot, Executive Director of UNAIDS to the National Convention of the Indian Parliamentary Forum on HIV/AIDS, New Delhi, India, 26 July 2003. www.unaids.org/html/pub/media/speeches01/piot_newdelhi_260703_en_doc.htm.