THE KAISER MEDIA FELLOWSHIPS IN HEALTH

Reporting Manual on HIV/AIDS: INDIA

October 2005

October 2005

This reporting guide on HIV/AIDS has been designed for journalists in India who are covering the global epidemic, often on short notice. It is intended as a working reference manual – to provide a brief background to many of the important issues that journalists need to consider in their reporting on HIV/AIDS. The material covers a broad range of subjects including the science, treatment and prevention of HIV/AIDS – it also discusses the ethical challenges of reporting on these issues. The HIV/AIDS epidemic is not only a battle against a virus: it can also be a battle about ideas, cultural taboos, stigma and discrimination. This guide includes suggestions about the use of language in reporting on HIV, as well as references to a basic list of sources for further information. The manual is intended to help journalists with their reporting on HIV/AIDS, in the belief that journalists have a significant role to play in informing the public and public officials – and a responsibility to do so in an informed way.

This version of the manual is specifically intended to help inform reporters in India. It was developed by a group of senior Indian health and medical journalists who have reported extensively on HIV/AIDS issues, and also includes expert input from non-governmental agencies working on the legal aspects of the epidemic. It builds off a more general global guide for reporters published by the Kaiser Family Foundation (available on the Kaiser Family Foundation website at www.kff.org or www.globalhealthreporting.org). Sections were added or amended to make this version of the manual more relevant for journalists reporting on HIV/AIDS in India. The project is part of a wider effort by the Kaiser Family Foundation to help journalists in India and across the globe in reporting on HIV/AIDS and related public health issues, through the Project for International Health Journalism. This is funded through a generous grant from the Bill & Melinda Gates Foundation. Suggestions of ways to expand or improve this reference guide, or for any other feedback regarding this manual, please send e-mail to mediafellows@kff.org.

The Kaiser Family Foundation is a U.S. non-profit, private operating foundation headquartered in Menlo Park, California. The Foundation is dedicated to providing information and analysis on health care issues to policymakers, the media, the healthcare community and the general public. It is not associated with Kaiser Permanente or Kaiser Industries. For more information about the Foundation and its programs, visit www.kff.org.

2400 SAND HILL ROAD MENLO PARK, CA 94025 USA +1 650 854-9400 FAX: +1 650 854-4800
EMAIL: MEDIA FELLOWS@KFF.ORG
WWW.KFF.ORG WWW.KAISERNETWORK.ORG WWW.GLOBALHEALTHREPORTING.ORG

TABLE OF CONTENTS

Acronyms	1
Glossary	3
HIV/AIDS: India's Many Epidemics	13
Timeline of HIV/AIDS in India	19
HIV/AIDS in India Fact Sheet	20
Ethics in Reporting on HIV/AIDS	22
Real life Issues in HIV/AIDS Reporting	26
FAQs About HIV/AIDS	28
FAQs on Covering HIV/AIDS	31
Sensitive Language	33
Issues in Pre-Marital Testing	36
Anti-Retroviral Drugs in India	38
FAQs on Patents	43
Important Terms in Antiretroviral Therapy	45
FDA-Approved Antiretroviral Therapy	46
Opportunistic Infections	50
Key Figures	54
India Contacts	61

This reporting guide was made possible thanks to the expert contributions of a group of senior Indian health and medical journalists. The project was led by Kalpana Jain, the former health editor at the Times of India and the author of Positive Lives, a moving narrative about the struggle of people living with HIV (published 2002 by Penguin Books India). Ms. Jain is currently a Kaiser International Health Journalism Fellow, and is based in New Delhi.

Other contributors include in alphabetical order: Pallava Bagla, chief correspondent, South Asia, for Science magazine; Mohuya Chaudhuri, News Editor City, NDTV; Subhadra Menon, health and science writer and author, No Place To Go: Stories of Hope and Despair from India's Ailing Health Sector (published 2004 by Penguin Books India); and Toufiq Rashid, principal correspondent, The Indian Express. The Lawyers Collective contributed expert advice and information regarding legal issues and the HIV/AIDS epidemic.
We are grateful to Science magazine for permission to reprint Jon Cohen's article on AIDS in India, and to Malcolm Linton for permission to reprint his photographs.

ACRONYMS

ACRONYM	DESCRIPTION
3 x 5	Three by Five
ABC	Abstinence, Be faithful, Condom Use
AIDS	Acquired Immuno Deficiency Syndrome
ANC	Ante Natal Clinic
ARV	Anti Retro Virals
ART	Anti retroviral Therapy
AZT	Zidovudine
BSS	Behavioral Surveillance Surveys
BSS	Behavioral Sentinel Surveillance
CDC	Centres for Disease Control and Prevention (U.S.)
CSW	Commercial Sex Workers
CNN	Condoms, Needles, Negotiation
DOTS	Directly Observed Treatment or Therapy Short-course for tuberculosis
ELISA	Enzyme-Linked Immunosorbent Assay
FHAC	Family Health Awareness Campaign
FRU	First Referral Units
FSW	Female Sex Workers
GIPA	Greater Involvement of People Living with and directly affected by HIV/AIDS
HAART	Highly Active Antiretroviral Therapy
HCV	Hepatitis C Virus
HIV	Human Immuno-deficiency Virus
ICMR	Indian Council of Medical Research
IEC	Information, Education and Communication
IDUs	Intravenous Drug Use
IAVI	International AIDS Vaccine Initiative
MSM	Men having Sex with Men
MDR-TB	Multi Drug Resistant Tuberculosis

ACRONYM	DESCRIPTION
NACO	National AIDS Control Organization
NACPI	National AIDS Control Programme, Phase 1
NACPII	National AIDS Control Programme, Phase 2
NACPIII	National AIDS Control Programme , Phase 3
PEPFAR	President's Emergency Plan for AIDS Relief (U.S.)
PLWHAs	People Living with HIV/AIDS
PPTCT	Prevention of Parent to Child Transmission of HIV
SACS	State AIDS Control Organization
SAEP	School AIDS Education Programme
STI	Sexually Transmitted Infections
STD	Sexually Transmitted Diseases
TIs	Targetted Interventions
UNAIDS	UN Joint programme on HIV/AIDS
VCTC	Voluntary counseling and testing centers
WHO	World Health Organization

GLOSSARY

A

1. **ABC**
   A – Abstaining from sexual activity or delaying the age of first sexual experience.
   B – Be faithful or mutual monogamy with an uninfected partner
   C – Correct and consistent condom use
   The ABC approach to behavior change promotes the adoption of these three behaviors as central to HIV prevention efforts.

2. **Abstinence**
   Refraining from sexual activity. In the context of HIV/AIDS, this term also refers to delaying the age of first sexual experience.

3. **Accidental Exposure or Accidental Transmission**
   This usually refers to HIV transmission that occurs in the health care setting. Transmission can occur from patient to provider or vice-versa.

4. **Acute HIV Infection**
   The first stage of HIV infection, this is the period immediately following infection with HIV. The length of the acute stage can last anywhere from a few days to several weeks. HIV multiplies rapidly and can be transmitted to others during this time. Acute HIV infection is also known as primary HIV infection (PHI).

5. **Affected Community**
   Persons living with HIV/AIDS, and other related individuals including their families and friends, whose lives are directly influenced by HIV infection and its physical, social and emotional effects.

6. **AIDS**
   Acquired Immuno Deficiency Syndrome (AIDS) occurs when an individual's immune system is weakened by HIV to the point where they develop any number of diseases or cancers. People who haven't had one of these diseases or cancers, but whose immune system is shown by a laboratory test to be severely damaged are also considered to have progressed to an AIDS diagnosis.

7. **AIDS-defining illness**
   These include a variety of conditions that occur at late stages of HIV disease and that signal progression to AIDS. According to UNAIDS, many individuals first become aware of their infection at this stage.

8. **AIDS Dementia Complex (ADC)**
   AIDS Dementia Complex, also known as HIV Dementia, is a condition caused by HIV that affects the brain and causes a person to lose their mental ability. Symptoms include loss of coordination and interest in one's surroundings, mood swings, and mental dysfunction. Memory loss and limited mobility can also develop. ADC usually occurs after a person has developed serious opportunistic infections, but can also occur at an earlier stage. ADC can be prevented and treated with antiretroviral therapy.

9. **Antenatal**
   Occurring before birth.

10. Antibodies

Molecules in the body that identify and destroy foreign (unfamiliar) substances such as bacteria and viruses. HIV tests identify whether or not antibodies to HIV (HIV antibodies) are present in the blood. A positive HIV test signals that antibodies are present.

11. Antiretroviral Therapy (ART)

ART refers to any of a range of treatments that include antiretroviral medications. These drugs are designed to destroy retroviruses such as HIV, or interfere with their ability to replicate.

12. Asymptomatic

A person with HIV is asymptomatic if they do not show signs and symptoms of the disease. This is also the second stage of HIV disease progression and can last for many years after infection. The virus can be transmitted during this stage.

C

13. Care & Treatment

Care and treatment encompass the range of interventions necessary to take care of people living with HIV/AIDS, including ***antiretroviral therapy***, treatment and prevention of ***opportunistic infections***, nutrition support, psychological and community support.

14. CD4 (T4) cell/ count

These cells control the body's immune response against infections and are the primary targets for HIV. HIV multiplies within these cells and eventually destroys them. As a result, the immune system becomes progressively weaker. CD4 cell count is used as one measure of HIV disease progression. The lower a person's CD4 cell count, the more progressive the HIV disease and deterioration of the immune system.

15. U.S. Centers for Disease Control & Prevention (CDC)

The United States Federal agency responsible for protecting individuals' health and safety. CDC's activities emphasize disease prevention, control, health education and health promotion. CDC also conducts international prevention activities for HIV, TB, malaria and other diseases.

16. Clinical Trial

A scientific study designed to evaluate the safety, ***efficacy*** and medical effects of a treatment (e.g. ***antiretroviral therapy***, ***vaccine***) in humans. A treatment must proceed through several phases of clinical trials before it is approved for use in humans.

17. CNN

C - Condom use
N - use clean Needles
N - Negotiating skills
CNN is an approach to behavior change that promotes the adoption of these three behaviors as central to HIV prevention efforts, especially in areas where injection drug use (IDU) is responsible for a significant portion of HIV transmission. Some consider CNN to be an alternative or addition to the ABC method, which promotes abstinence, being faithful and condom use.

18. Combination therapy

The use of two or more antiretroviral drugs in combination. The use of three of more antiretroviral drugs is referred to as ***HAART*.**

19. Cross Resistance

The phenomenon where HIV resistance to one drug (see ***drug resistance***) prompts resistance to other drugs in the same class.

D

20. DDT

DDT (dichlorodiphenyltrichloroethane) was the main insecticide used during the 1950s and 1960s in the World Health Organization's (WHO) global campaign to eradicate the mosquitoes that carry malaria. DDT has a history of being a highly controversial insecticide. It has been banned from agricultural use in almost all countries. Currently, the WHO recommends use of DDT for malaria control through indoor spraying. Through WHO's efforts, malaria was successfully eradicated from North America and Europe.

21. Down Low

The practice of men having sex with men and withholding this information from others. These men may also be having sexual relations with women who are sometimes unaware of their partners' activities.

22. Drug-drug interaction

A situation where a drug changes the way another drug works in the body, also known as a *synergistic effect*. This can result in increased or decreased effectiveness of either drug. Drug-drug interactions can also lead to unintended side effects.

23. Drug resistance

The ability of HIV to reproduce despite the presence of anti-HIV drugs. Drug resistance results from mutations that arise during HIV replication.

E

24. Efficacy

The measurement of a drug's or treatment's ability to heal, regardless of dose. For example, the efficacy of an ***antiretroviral*** drug is the most benefit that the drug can cause without considering how much of the drug is taken.

25. Endemic

The constant presence of a disease or infectious agent within a given geographic area or population group; can also refer to the usual prevalence of a given disease within such area of group.

26. End-stage disease

The four stages of HIV disease are acute infection, asymptomatic, chronic symptomatic and AIDS. Although AIDS is the end-stage of HIV disease, it is possible to live for years after an AIDS diagnosis given appropriate drug therapy.

27. Epidemic (types- low, concentrated, generalized)

The occurrence of more cases of disease than expected in a given area or among a specific group of people over a particular period of time.

There are different ways to describe the distribution of an HIV epidemic in an area:

- Low-level HIV prevalence is low across the general population and is still low among higher-risk sub-populations
- Concentrated HIV prevalence does not exceed 1% in the general population but does exceed 5% in some sub-populations (eg. among sex workers, IDU, MSM).
- Generalized HIV prevalence exceeds 1% in the general population

F

28. Fixed dose combination (FDC)

Fixed dose combination treatment refers to a combination of two or more drug products, such as antiretrovirals, in a single pill. The use of these single-pill combinations is essential to the *3 by 5* initiative because they are practical for use in resource-limited settings. An example of FDC is the single-pill combination of stavudine, lamivudine and nevirapine.

G

29. Generic

A drug that is identical, or bioequivalent, to a brand name drug in dosage, safety, strength, how it is taken, quality, performance, and intended use. The generic name of a drug is the common name of a drug, which is not protected under any manufacturer's copyright. It is the more commonly used format when referring to a drug in medical literature or the media. Generic also refers to less expensive, but chemically identical, medications manufactured by companies that did not invent the drug. In some countries, generic drugs come on the market after a patent on the drug has expired. In other countries, generic drugs are manufactured and sold even before a patent expires.

30. Global Fund

The Global Fund to Fight AIDS, Tuberculosis and Malaria was created in 2001 at the urging of UN Secretary General Kofi Annan. The Global Fund is a partnership among governments, the private sector and affected communities. It is an independent grant-making organization whose purpose is to help developing countries fight AIDS, tuberculosis and malaria.

H

31. Highly Active Antiretroviral Treatment (HAART)

A course of treatment that involves the use of three or more antiretrovirals.

32. HIV test

HIV-tests test for the presence of HIV antibodies in the blood. HIV antibodies are molecules produced by the body once it detects the presence of HIV. The production of HIV antibodies does not happen immediately after exposure to the virus and the period after infection before production of antibodies is called the window period. During the window period, an HIV test may be negative. It is possible to test negative despite the presence of HIV in the body. There are several different kinds of HIV tests used to screen for the presence of antibodies.

33. Human Immunodeficiency Virus (HIV)

The virus that causes AIDS. HIV is transmitted through infected blood, semen, vaginal, secretions, breast milk, and during pregnancy or delivery. There are two types of HIV, HIV-1 and HIV-2. Both are transmitted through the same methods/manners and result in progression to AIDS. HIV-1 is responsible for the overwhelming majority of global infections, whereas HIV-2 is less widespread and primarily found in West Africa.

I

34. IDU

IDU stands for Injection Drug Users, and refers to individuals who use needles to inject drugs.

35. Immune system

The body's system of defense against foreign organisms such as bacteria, viruses, or fungi.

36. Immunodeficiency

A state where the immune system cannot defend itself against infection. HIV progressively weakens the immune system and causes immunodeficiency.

37. Immunosuppression

A state where the immune system cannot function normally because it has been weakened. This can arise from drugs and medical treatments (chemotherapy) or diseases (HIV). An immune system that is immunosuppressed may also be referred to as immunocompromised.

38. Incidence

The number of new cases of a disease in a population over a specific period of time (eg. annual number of new HIV cases in a country).

39. Incubation period

The period of time between HIV infection and the onset of symptoms.

M

40. MDR-TB

Acronym for "multidrug resistant tuberculosis". A strain of tuberculosis that is resistant to two or more anti-TB drugs. MDR-TB usually arises when people take only enough medication to feel better, but not the full amount prescribed by a physician.The weaker bacteria are killed, but the stronger bacteria survive and reproduce. These stronger bacteria, when fully grown and causing sickness again, will not be curable with the same treatment and require larger doses of the drug or an entirely new, stronger drug. MDR-TB is a large problem in developing countries, where continual supervision of treatment is not always possible.

41. Microbicides

Microbicides are products designed to reduce the transmission of microbes. Research is underway to determine whether microbicides can be developed to successfully reduce the transmission of sexually transmitted diseases, including HIV. Microbicides would be applied topically, either in the vagina or anus and could be produced in many forms, including films, creams, gels, suppositories or as a ring or sponge that releases the active ingredient over time.

42. Mother-to-child transmission

This refers to transmission of HIV from an HIV-positive mother to her child during pregnancy, labor and delivery or breastfeeding. Transmission from mother to child is also referred to as perinatal and vertical transmission.

43. MSM

MSM stands for Men who have Sex with Men. For assessing disease risk, use of the term "MSM" may be preferable to "gay" , "homosexual" or "bisexual" because it refers to a risk behavior, rather than an identity that may or may not be tied to a behavior. In many countries and cultures, men who have sex with other men may not perceive themselves as gay or bisexual.

44. Multidrug Resistant Tuberculosis (MDR-TB)

See *MDR-TB*.

45. Mutation

A change in an organism's genetic structure that arises during the process of multiplication. HIV multiplies quickly and changes form during the process. These changes allow for the formation of ***drug resistant*** strains of the virus.

N

46. National AIDS Control Organisation (NACO)

In India, the National AIDS Control Organisation (NACO) carries out the country's national AIDS programme, which includes formulation of policy and implementation of prevention and control programmes. It was established in 1993 and is now running the second phase of the National AIDS Control Project (NACP-II). The first phase (NACP-I) ended in March 1999. The second phase of the National AIDS Control Programme (NACP-II) started in November 1999. Its term has been extended to March 2006.

In 1989, with the support of WHO, a medium term plan for HIV/AIDS control was developed. With a US $10 million budget, it was implemented in five most affected states. The actual prevention activities gained momentum by 1992 and the national programme became more formalised with the establishment of NACO in 1993.

O

47. Opportunistic Infections (OI)

Diseases that rarely occur in healthy people but cause infections in individuals whose ***immune systems*** are compromised as a result of HIV infection. These organisms are frequently present in the body but are generally kept under control by a healthy immune system. When a person infected with HIV develops an OI, they are considered to have progressed to an AIDS diagnosis.

P

48. Pandemic

A worldwide epidemic; occurring over a wide geographic area and affecting an exceptionally high proportion of the population.

49. Pathogen

A substance or organism that causes disease.

50. PEPFAR

US President George Bush's Emergency Plan for AIDS Relief (PEPFAR) is a US$ 15 billion, 5 year initiative, beginning in 2004 to address HIV/AIDS, TB, and malaria in developing countries. It includes almost US $10 billion in new money targeted at 15 focal countries and for the Global Fund. In 2005, President Bush pledged to increase funding for malaria prevention and treatment by more than $1.2 billion over five years. To date, PEPFAR has supported anti-retroviral treatment for approximately 235,000 men, women, and children in Africa, Asia and the Caribbean. PEPFAR was authorized by the United States Leadership Against HIV/AIDS, Tuberculosis, and Malaria Act of 2003.

51. Perinatal transmission

Transmission of HIV from an HIV-positive mother to her child during pregnancy, labor and delivery or breastfeeding. Perinatal transmission is also known as mother-to-child and vertical transmission.

52. Placebo

A substance that resembles a real medication but has no medical effect.

53. PPTCT

PPTCT stands for "prevention of ***parent-to-child transmission***." UNAIDS outlines a three-part strategy to prevent HIV transmission from an HIV-positive mother to her child.

a. Protect females of child-bearing age against HIV infection
b. Avoid unwanted pregnancies among HIV-positive women
c. Prevent transmission during pregnancy, delivery and breastfeeding by providing voluntary counseling and testing, ***antiretroviral therapy***, safe delivery practices and breast milk substitutes when appropriate.

54. Prevalence

Prevalence is a measure of the proportion of the population that has a disease at a specific period in time.

55. Prevention (primary, secondary)

In the context of HIV, prevention activities are designed to reduce the risk of becoming infected with HIV (primary prevention) and the risk of transmitting the disease to others (secondary prevention). Prevention services include voluntary counseling and testing, condom distribution, disease surveillance, outreach and education, and blood safety.

56. Primary HIV infection (PHI)

The first stage of HIV infection, this is the period immediately following infection with HIV. The length of this stage can last for several weeks. HIV multiplies very often and can be transmitted to others during this time. PHI is also known as *Acute HIV Infection*.

57. Prophylaxis

Prophylaxis refers to the prevention or protective treatment of disease. Primary prophylaxis refers to the medical treatment that is given to prevent onset of an infection. Secondary prophylaxis refers to medications given to prevent recurrent symptoms in an existing infection.

58. PWA / PLWA / PLWHA

These are acronyms for "Person or people with HIV/AIDS" and "Person or people living with HIV/AIDS."

R

59. Risky behavior

This refers to any behavior or action that increases an individual's probability of acquiring or transmitting HIV. Some examples of risky behaviors are having unprotected sex, having sex with multiple partners and injecting drugs. Alcohol use has also been linked to risky behavior because of its effect on an individual's ability to make decisions and negotiate safer sex.

S

60. Sexually transmitted disease/infection (STD/STI)

Any disease or infection that is spread through sexual contact.

61. Social marketing

Social marketing techniques have been used worldwide to promote a range of HIV-related prevention techniques including condom use. Social marketing refers to the adaptation of commercial marketing techniques to achieve social goals and encourage the adoption of healthier behavior.

T

62. Tuberculosis

Tuberculosis is a bacterial infection caused by *Mycobacterium tuberculosis*. The disease usually affects the lungs but can spread to other parts of the body in serious cases. An individual can become infected with TB when another person who has active TB coughs, sneezes, or spits. Not all people who become infected with TB develop symptoms. Those who do not become ill are referred to as having latent TB and cannot spread the disease to others.

U

63. UNAIDS

This acronym refers to the Joint United Nations Programme on HIV/AIDS. It is a part of the UN and is a collaboration among ten organizations.

V

64. Vaccine

A substance that contains a deactivated infectious organism designed to stimulate the immune system to protect against subsequent infection from the active organism. A preventive vaccine preempts infection from that organism. A therapeutic vaccine improves the ability of the immune system of a person already infected with the organism, to defend itself.

65. VCT

'Voluntary Counseling and Testing' programs are a critical component of both HIV prevention treatment activities. VCT is an internationally accepted intervention designed to enable people to learn their HIV status and receive counseling about risk reduction and referral to care if they are HIV positive.

66. Vertical Transmission

Transmission of HIV from an HIV-positive mother to her child during pregnancy, birth or breastfeeding. Vertical transmission is also referred to as mother-to-child and perinatal transmission.

67. Viral Load

The amount or concentration of HIV in the blood. There is a correlation between the amount of virus in the blood and the severity of disease – the higher the viral load, the more progressive the HIV disease. A viral load test is an important tool for doctors in monitoring illness and determining treatment decisions.

68. Vulnerable populations

Populations that are at increased risk of exposure to HIV due to socioeconomic, cultural, or behavioral factors. Vulnerable populations include migrants, poor people, men who have sex with men, injection drug users, sex workers and females particularly in countries or communities where gender inequality is pronounced.

W

69. World Health Organization (WHO)

The WHO is the United Nations agency for health. It is governed by 192 member states, and aims to help all individuals achieve the highest possible level of health. It is internationally recognized as one of the leading organizations dedicated to global health. The WHO, together with UNAIDS, launched the 3x5 Initiative.

70. World Bank

The World Bank is a development Bank that provides loans, policy advice, technical assistance and knowledge sharing services to low and middle income countries to reduce poverty. As a sponsor of UNAIDS, the World Bank has committed over US $16 billion to fight the spread of HIV/AIDS.

REFERENCES

Schuettler, Darren. "Abstinence, Condom Controversy Erupts at AIDS Meet." *Reuters* 12 July 2004.

American Foundation for AIDS Research (Summer 2003). *Global Link: A Guide to International HIV/AIDS Research, Treatment, and Clinical Trials*. Vol. 2, No. 1, www.amfar.org/GlobalLink

CDC's Reproductive Health Information Source (May 2003) *Glossary of Epidemiology Terms*. http://www.cdc.gov/reproductivehealth/epi_gloss.htm

Foreman M. "ABC of HIV/AIDS." In Boafo, STK, Arnaldo, CA eds. *Media & HIV/AIDS in East and Southern Africa: A resource book*. UNESCO, 2000, http://www.unesco.org/webworld/publications/media_aids/index.html

HIV/AIDS Treatment Information Service. (Sep. 2002) *Glossary of HIV/AIDS-Related Terms, 4th ed*. http://www.aidsinfo.nih.gov/ed_resources/glossary/

Know HIV/AIDS. *Get the Facts: the basics,* http://www.knowhivaids.org/facts_basics.html#q2

National AIDS Control Organisation (NACO) http://www.nacoonline.org

Stine, G.J. AIDS Update 2003. New Jersey: Prentice Hall, 2003.

UNAIDS. *Q&A II: Basic Facts about the HIV/AIDS Epidemic and its Impact*. http://www.unaids.org/en/resources/questions_answers.asp

UNAIDS. *Q&A III: Selected Issues: Prevention and Care.* http://www.unaids.org/en/resources/questions_answers.asp

UNAIDS. (1998) *Social marketing: An effective tool in the global response to HIV/AIDS.* http://www.unaids.org/publications/documents/supporting/communications/una98e26.pdf

United Nations Development Programme, YouandAIDS, India at a Glance, http://www.youandaids.org

United Nations Population Fund. (2003) "Promoting Healthier Behavior." In *State of the World Population 2003: Investing in Adolescents' Health and Rights*. http://www.unfpa.org/swp/swpmain.htm

World Health Organization and UNAIDS. (2002) *Second Generation Surveillance for HIV/AIDS.* http://www.who.int/hiv/topics/surveillance/2ndgen/en/

World Health Organization. *The "3 by 5" Target Newsletter,* February/July 2005

Ward, D.E. AmFAR AIDS Handbook: The complete guide to understanding HIV/AIDS. New York: W.W. Norton & Company, Inc., 1998.

Reprinted with permission from Science 23 April 2004; 304:504-509 [DOI: 10.1126/science.304.5670.504] and from Malcolm Linton for his photographs

HIV/AIDS:

CHENNAI—Pacing restlessly in front of her husband, who lies comatose in a hospital bed here, a 23-year-old woman spills out a tragic story. A bookbinder by trade, her husband, 29, has meningitis, caused by an opportunistic infection that flourishes during late-stage AIDS. She holds an infant in her arms and keeps an eye on their 4-year-old boy, whose birth transformed their lives. During that pregnancy a blood test determined that she was infected with HIV. "The doctor told my husband, not me," the woman explains. "My husband tore up the results and told me there won't be anything there. Then he quietly went to get tested himself." She soon learned the truth, and a test of their son revealed that the virus had passed to him, too. The news quickly traveled to their neighbors. "They avoid us," the woman says. "They are afraid." So is she.

The couple have no income except for money her sister gives them. They live 400 kilometers from here, but in desperation they made the 9-hour train trip to the massive Government Hospital of Thoracic Medicine, the old Tambaram Sanatorium for tuberculosis. Located just outside Chennai (formerly Madras)—the sprawling capital of south India's Tamil Nadu state—Tambaram has developed a reputation over 75 years for rescuing people from death's door. "They come with lots of hope," says one of the bookbinder's doctors, Satagopa Kumar. "They think coming to Tambaram will be a cure. We have to tell them slowly." Kumar and his colleagues are delivering their sad message to a staggering number of people these days.

Tambaram—which spreads out over 45 hectares and has cows and pigs roaming under the giant banyan trees that shade the grounds—sees more HIV-infected patients than any hospital in India. Last year alone, Tambaram admitted nearly 10,000 HIV-

This is the second in a series of articles on HIV/AIDS in Asia, leading up to the XV International AIDS Conference to be held in Bangkok, Thailand, in July. The first part, on southeast Asia, was published in the 19 September 2003 issue (www.sciencemag.org/sciext/aidsasia).

Reporting for this series was supported in part by a fellowship to Jon Cohen from the Kaiser Family Foundation. Photographs are by Malcolm Linton.

India's Many Epidemics

infected people and saw 120,000 more as outpatients—double the load in 2001. Only a tiny percentage of the patients can afford to buy lifesaving anti-HIV drugs, although a government program announced in November promises to provide them for free to the country's neediest. "This institution is not functioning in the ideal situation," says superintendent P. Paramesh, who welcomes a recent $5 million infusion from the U.S. Centers for Disease Control and Prevention to help upgrade the facility. "We're able to do what we're able to do."

Each of the five AIDS wards for men, including the one housing the bookbinder, has three dozen beds and few vacancies. Today, the two AIDS wards that care for women and eunuchs have resorted to their overflow strategy: offering new inpatients thin straw mats on the tile floor. Pediatrics has yet another ward devoted to AIDS.

As Kumar walks the wards in his white lab coat, patients and relatives call out, desperately pleading for help. "Most people don't know the incidence of HIV in the community," says Kumar. "When they come here, they know."

Denominator problem

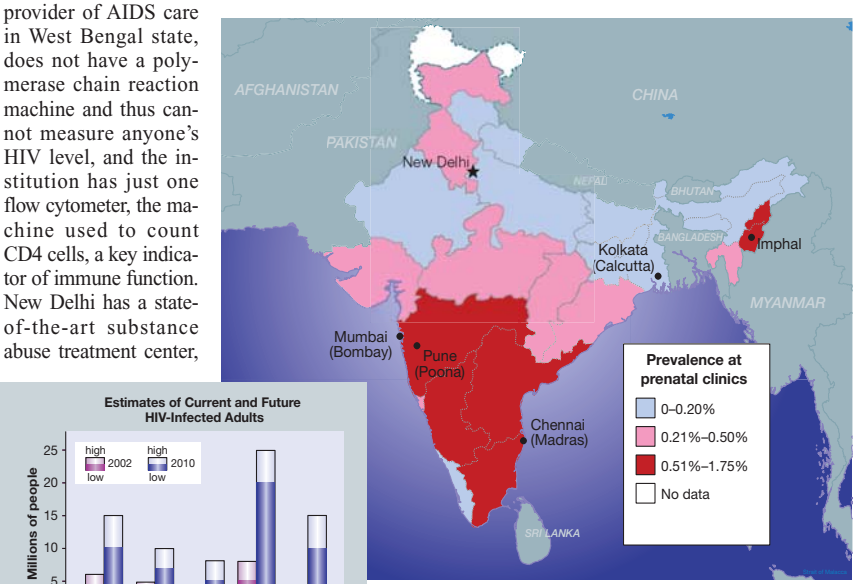
India shares one time zone, but more than 1 billion people live in its vast regions, and they speak different languages, practice different religions and customs—and face different AIDS epidemics. Heterosexual transmission accounts for 85% of the country's estimated 3.8 million to 4.6 million HIV infections, but in some areas, such as Manipur state in the Northeast, injecting drug use (IDU) drives the spread. In the slums of Pune, HIV has made serious inroads, but in similar conditions in Chennai a recent study found few infections. Sex workers in Kolkata have joined a union that promotes condom use and, research shows, has helped keep their HIV prevalence down to 11%, well below the 50% found in the red-light districts of Mumbai and Pune (see sidebar on p. 506).

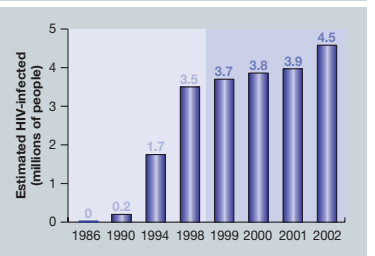
Since 1992, the federally run National AIDS Control Organisation has coordinated the country's response to the epidemic, yet huge differences in resources exist geographically, and not always for obvious reasons. Pune's National AIDS Research Institute (NARI) and Chennai's Tuberculosis Research Centre have the latest scientific equipment, allowing investigators to characterize everything from HIV strains (mostly the "subtype C" seen in Africa) to individual viral levels and the resultant immune damage.

In contrast, the School of Tropical Medicine in Kolkata, the main government provider of AIDS care in West Bengal state, does not have a polymerase chain reaction machine and thus cannot measure anyone's HIV level, and the institution has just one flow cytometer, the machine used to count CD4 cells, a key indicator of immune function. New Delhi has a state-of-the-art substance abuse treatment center, whereas in Manipur, most of the HIV prevention and care for IDUs comes from nongovernmental organizations run by former users (see p. 509).

In January, *Science* visited AIDS researchers, caregivers, patients, community workers, and people at high risk of becoming infected in Pune, Kolkata, New Delhi, Manipur, and Chennai. Although the epidemic differs from place to place, similar forces across the country aid and abet the spread of HIV, including strong taboos about discussing sex, the limited power that many women have (see p. 513), and widespread discrimination against the infected. India also has a massive population of mobile workers and the largest number of people living beneath the World Bank poverty line of $1 per day. Many AIDS experts say they're deeply worried about where the Indian epidemic is headed, and a wave of international aid has started to pour in, including a $200 million commitment from the Bill & Melinda Gates Foundation.

Epidemiologist Richard Feachem, head of the Global Fund to Treat AIDS, Tuberculosis and Malaria—which has awarded India $153 million—says the country could become *the* major epidemic in the world. "If we look at the current response in India, they're much better than 2 or 3 years ago, but it still falls way short of what's necessary to attenuate a looming disaster," says Feachem. "India is well on the way to a huge and explosive





Mapping a strategy. India will first offer free anti-HIV drugs to people living in the six states with the highest prevalence (*above*, in maroon). HIV infections have steadily climbed nationwide (*lower left*). A report by the National Intelligence Council caused a furor with its prediction that India could have 25 million cases by 2010 (*top left*).

SOURCE (MAP AND PROJECTIONS) U.S. NATIONAL INTELLIGENCE COUNCIL; (BOTTOM BAR GRAPH) INDIAN NATIONAL AIDS CONTROL COUNCIL

Sonagachi Sex Workers Stymie HIV

KOLKATA—At the edge of the kaleidoscopic outdoor bus depot that occupies several downtown blocks here, dozens of women in multicolored saris, some toting children, step into two well-worn buses this temperate January morning. It seems like a perfectly unremarkable sight, except for one detail: The women are sex workers from the city's Sonagachi red-light district. They belong to the Durbar Mahila Samanwaya Committee (DMSC), a quasi–trade union that today will bus them 200 kilometers for a 4-day retreat. In all, 800 people will attend to review the union's many programs, the most celebrated of which has kept the HIV prevalence in these women down to 11%. "With sex workers everywhere else, within 3 to 4 years, the prevalence has just skyrocketed," says Smarajit Jana, the epidemiologist who 12 years ago started what's widely known as the Sonagachi Project.

Jana, who left the project in 1999 and now works in New Delhi for the relief agency CARE India, holds what DMSC president Debasish Chowdhury Digha calls a "demigod" status among the sex workers. "His idea was totally different," says Digha. "Dr. Jana realized that sex workers could run the project. No one could accept that. Only Dr. Jana thought about sex workers and their families."

Featured in the international media and celebrated as a "model" effort by the World Health Organization, the Sonagachi Project set up a health clinic and hired sex workers for "peer outreach." Wearing distinctive coats over their saris, the women gave out free condoms and spread the word about HIV and AIDS. They negotiated with madams, police, and what Jana calls the "local ruffians" who run the sex industry, convincing them that using condoms protected their investments. Tired of dealing with loan sharks, they opened their own bank to lend one another money. Condom use soared and HIV prevalence crept up slowly, whereas the prevalence in the red-light districts of Pune, Mumbai, and Goa has topped 50%. "Sonagachi has not been replicated in many parts of India," says N. K. Ganguly, who heads the Indian Council of Medical Research. "We need to know why."

Sisterhood is powerful. Debasish Chowdhury Digha heads the Sonagachi Project's sex worker union.

Teasing out the answer has become the subject of several investigations—including a $1 million effort under way by DMSC that's funded by the Bill & Melinda Gates Foundation. "We want to break this myth that it's not replicable," says Jana. "We'll do it in broad daylight."

There is some scientific evidence that the Sonagachi model can succeed in other Indian settings. Working with Jana and Sonagachi outreach workers, a team led by psychologist Mary Jane Rotheram-Borus of the University of California, Los Angeles, conducted a controlled study for 16 months that compared 100 sex workers from one community in West Bengal state who'd received "enhanced intervention" with 100 sex workers in another. All the women who received the enhanced intervention—which repeated the Sonagachi strategy of having peer outreach workers advocating for sex workers and "empowering" the women—reported using condoms more frequently than those in the control group. (The researchers tested for sexually transmitted diseases to validate this, but too few occurred for a meaningful analysis.)

Rotheram-Borus cautions sex workers who want to replicate Sonagachi that it did not begin as an empowerment movement. "It requires support initially from high-status persons within their culture who have political and social clout," she says. "Other groups of sex workers would need, I think, the type of supports that the Sonagachi have had: highly educated volunteers mobilized initially by Jana who trained, supported, and shared their social status with the sex workers."

Sex workers elsewhere in India have taken notice of Sonagachi's success. "They have a great union," says Mary D'Souza, who runs Saheli, a sex worker group in Pune, and spent time in Sonagachi. "I want to create the Sonagachi Project here." **–J.C.**

epidemic. It's about 15 years behind Africa, but it's on the same trajectory."

From an official vantage point, HIV has infected roughly 4 million, or only 0.8%, of the adults between 15 and 49 years old—just a smidgen higher than the prevalence in the United States and European countries. But Peter Piot, head of the Joint United Nations Programme on HIV/AIDS (UNAIDS), cautions that the impact of the country's epidemic is obscured by "the denominator problem": India's huge population. A seemingly low national prevalence can equal a huge number of infected people; India now accounts for at least 10% of the world's HIV infections and is second only to South Africa.

Although neither Piot nor Feachem expects that a country of India's size will reach South Africa's 20% adult prevalence rate nationwide, both emphasize that such comparisons make little sense. "Each state in India is bigger than most African countries," says Piot. (Indeed, 10 have larger populations than South Africa.) Feachem says "there's nothing to prevent 20% prevalence of adults" in particular states.

Faced with steadily increasing patient loads, many AIDS clinicians here strongly suspect that the country already has a much higher prevalence than reported. "I'd say there are approximately 5 to 10 million infected people," asserts Suniti Solomon, one of the clinicians who described India's first AIDS cases in 1986 and now heads YRG CARE, an HIV/AIDS education, care, research, and training nonprofit in Chennai.

In 2002, the U.S. National Intelligence Council (NIC) caused an uproar when it issued the dire prediction that by 2010, HIV could infect up to 25 million Indians, or about 5% of the adult population. This would roughly equal the total number of adult infections in all of sub-Saharan Africa today. Shortly after the report came out, then–Health Minister Shatrughan Sinha publicly criticized U.S. Ambassador Robert Blackwill and Microsoft CEO Bill Gates for referencing the figures, saying, "I fail to understand how people holding such important positions can stand on our soil and say that India will have 25 million sufferers of AIDS by 2010."

N. K. Ganguly, an immunologist who heads the Indian Council on Medical Research (ICMR)—the country's counterpart to the U.S. National Institutes of Health (NIH)—thought the NIC report widely missed the mark. "The projections have no basis in fact," says Ganguly, who is based in New Delhi. Although Ganguly acknowledges his country's initial missteps in combating HIV—"we went through a lot of hiccups," he says—he also thinks its efforts have made some headway: "The way AIDS should have increased, it has not. We have not become South Africa."

Besieged brothels. Mary D'Souza (right), who runs the sex worker group Saheli in Pune, hopes to replicate the success of Kolkata's Sonagachi Project (see sidebar on p. 506).

Robert Bollinger, an AIDS epidemiologist at Johns Hopkins University in Baltimore, Maryland, who has worked extensively in the country for the past 12 years, says the prevalence debate reflects the fact that researchers rely on "sentinel" sites in the major cities, which sample groups such as pregnant women, sex workers, and IDUs. "All of the estimates are based on limited information about what's happening in rural areas," says Bollinger. "Does that mean they're overestimates or underestimates? Until we get data, it's difficult to say."

Solomon, for one, welcomed the NIC report because she believed it helped spur the government to launch its ambitious new program to supply anti-HIV drugs to 100,000 people by the end of 2005. "The whole thing was a big mess," says Solomon, who thinks the Indian government's reaction to the report was overblown. "But India has to be pushed for everything." And John Fahey of the University of California, Los Angeles (UCLA)—another AIDS epidemiologist who has a long history of working in India—says the government's new treatment program will help sharpen estimates. "With the availability of antiretrovirals, it will become easier to do surveillance as an HIV test is no longer a death sentence and there's less stigma," says Fahey.

Ramesh Paranjape, director of NARI, echoes the pragmatic perspective heard from many AIDS officials throughout Asia. "Whether HIV has infected 6 million or 8 million people here, our responsibility is not going to change," Paranjape says.

Drug dilemmas

Around the time the bookbinder was admitted to Tambaram, another AIDS patient in a similar condition entered the upscale Ruby Hall Clinic across the country in Pune. The two cases followed different paths. The second man, the owner of a milk shop, had enough money for his wife to bring him to Ruby Hall, where the experienced AIDS team led by Sanjay Pujari diagnosed progressive multifocal leukoencephalopathy. Caused by an endemic virus that thrives in damaged immune systems, the disease best responds to anti-HIV drugs.

One-fourth of the HIV-infected patients who come to Ruby Hall Clinic receive anti-HIV drugs, and the milk seller's family assured the doctors that he had enough money to pay for an initial course of treatment. "They said he won't be able to afford them lifelong, but since the government [drug support] program is around the corner, he can afford to start now," says Ameet Dravid, a resident who cared for the man. By late January, the milk seller had markedly improved and could even speak a few words—in particular, "I want to go home." The clinic planned to discharge him later that day.

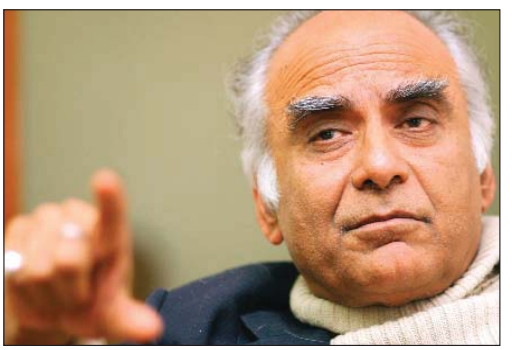
The new government program, which officially begins this month, offers a standard cocktail of free antiretroviral drugs, made by Indian generic manufacturers, to specific groups of infected people around the country. To receive the drugs, people must live in one of six states designated "high prevalence" (see map, p. 505). Only infected people who are under 15, are pregnant, or have full-blown AIDS qualify for the free treatment. The effort, says ICMR's Ganguly, is a "very courageous decision."

But soon after Health and Family Welfare Minister Sushma Swaraj unveiled the program on 30 November last year, clinicians across the country began debating the particulars and the staggering obstacles they face. "I strongly feel that antiretrovirals should be provided to all HIV needy patients in this country, but the process is very awkward," says Pujari. He particularly worries about the cost of monitoring people under treatment, which ideally requires measuring their levels of CD4 white blood cells and the amount of HIV in their blood. "Monitoring is more expensive than the drugs," says Pujari.

Pujari and others also fear that India cannot train its clinicians quickly enough. "The abuse of these regimens is already happening," says Vinay Kulkarni, a private practitioner in Pune who runs a busy HIV/AIDS clinic. "Many times, drugs are prescribed by doctors at the wrong dosages and the wrong combinations." This can quickly lead to drug-resistant strains. Kenneth Mayer, who heads the AIDS program at Brown University in Providence, Rhode Island, and collaborates with Solomon, notes, too, that India's generic manufacturers of anti-HIV drugs have little incentive to train doctors. In contrast, he says U.S. drugmakers, concerned about meeting Food and Drug Administration requirements, "bend over backward" to train clinicians in the proper use of new drugs.

Aside from cost and logistical issues, some AIDS clinicians have different ideas about who should receive treatment first. Subhasish Kamal Guha of the School of Tropical Medicine in Kolkata has seen his annual HIV patient load jump from 300 to 500 during the past 2 years, but West Bengal state does not qualify as a high-prevalence region. "Instead of singling out states, the poorest of the poor should be provided ARVs [antiretrovirals], regardless of where they live," says Guha.

At Chennai's Tuberculosis Research



Pointed reply. ICMR director-general N. K. Ganguly rejects dire predictions about the spread of HIV in India.

The National AIDS Research Institute's Long Reach

PUNE—At Byramjee Jeejeebhoy Medical College, a 25-year-old HIV-infected widow comes in to have her baby's blood tested for the virus, part of a clinical trial she has joined that aims to prevent transmission through breast milk. The blood samples will go across town to the National AIDS Research Institute (NARI) for analysis.

In the city's Yerawada neighborhood of cluttered tenements and wobbly shacks, George Swamy and his staff from the John Paul Slum Development Project provide home care, medicine, counseling, and meals to more than 300 patients with AIDS. NARI trained much of the staff and pays their monthly wage.

At an upstairs flat in Budhwar Peth that looks directly into the brothels across the street, sex workers receive free health care. NARI runs the clinic.

NARI is one of the world's only national research institutions dedicated to HIV/AIDS, and its tentacles reach all over Pune. Its headquarters, on a 3-hectare campus in an industrial neighborhood outside the city, houses a staff of 60 whose labs have a DNA sequencer to hunt for resistance mutations in HIV, polymerase chain reaction machines, flow cytometers, and phalanxes of computers. "NARI is the best equipped and most experienced HIV/AIDS research institute in India," says epidemiologist Robert Bollinger of Johns Hopkins University in Baltimore, Maryland.

Relatively resource-rich. Ramesh Paranjape, NARI's officer in charge, enjoys modern labs funded in part by the institute's extensive collaborations.

Bollinger had much to do with helping the institution become established. Set up by the Indian Council of Medical Research, NARI came to life in Pune because it could easily poach scientists from the venerable National Institute of Virology located here. In 1992, the nascent institute began a collaboration with Bollinger on a project funded by the U.S. National Institutes of Health (NIH) to prepare sites for AIDS vaccine efficacy trials. The project ultimately fizzled out because NIH became disillusioned with the performance of the lead vaccines in line for these trials, but the NARI researchers got their sea legs and began to develop a detailed understanding of the spread of HIV in Pune. "It was a huge boost for the program," says epidemiologist Sanjay Mehendale, NARI's deputy director. Bollinger remains tightly linked to many NARI projects. "He has been fantastic to collaborate with," says NARI's leader, immunologist Ramesh Paranjape. "We call him an honorary citizen of Pune."

NARI received half its $2.1 million budget this year from foreign grants and contributions, and its work now reaches far beyond epidemiology. A repository of Indian HIV isolates contains 190 strains. One novel study has looked for anti-HIV activity in 143 herbal preparations, which are hugely popular here. (None was found.) In the 27 March issue of *The Lancet*, a study by NARI and Hopkins researchers reported that circumcision gave men some protection from HIV but not from other sexually transmitted diseases, suggesting that cells in the foreskin may be extra-vulnerable to the AIDS virus. NARI also has plugged into NIH-funded clinical trials that involve discordant couples and vaginal microbicides (see main text). In a few months, NARI plans to launch a study with the International AIDS Vaccine Initiative of the first AIDS vaccine to be tested in India.

NARI has one obvious shortcoming: Its tentacles rarely stretch beyond Pune. "As a national institution we should have reached every place," agrees Paranjape. "And as we get more resources, we would like to do it."

–J.C.

Centre, Soumya Swaminathan argues that criteria for eligibility should include whether a person has tuberculosis. In a recent study, Swaminathan and her co-workers found that more than 40% of their HIV-infected patients who develop TB die within 2 years—and two-thirds of them succumb to other AIDS-related diseases. "Even though we do excellent treatment of TB and can cure this, their long-term outcome is very bad," says Swaminathan. Currently, TB patients who have a diagnosed coinfection with HIV can receive free antiretrovirals through the new program only if their CD4 counts drop below 200, which does not apply to about one-third of the patients Swaminathan sees.

As Solomon discusses her own misgivings about the new treatment program, a crow she once fed some biscuits to incessantly taps its beak on her office window. The crow provides an uncanny backdrop to the conversation: More and more HIV-infected people in India now know that drugs can extend their lives, and they desperately want them. "There may be chaos," says Solomon, who also fears that lack of training, monitoring, and funding will hamper the new program. "But we still need to do it."

Contradiction central

Three years ago, Niteen, 35, was hospitalized in Pune with pneumonia and tuberculosis. When the doctors diagnosed AIDS and explained that life-extending drugs existed, Niteen and his wife, Kavita, decided he had to have them, no matter the cost. The couple, who had a "love marriage" (as opposed to an arranged one) and have a 9-year-old boy, have had to sell their house to pay for Niteen's anti-HIV drugs. But the treatment, which Niteen receives through a clinic run by NARI, has turned his life around: His CD4 count has jumped from a life-threatening 28 to 325—well above the 200 level that denotes AIDS.

When Kavita and Niteen told their families about his infection, they offered both emotional and financial support. She remains uninfected, and unlike most married couples in India, they regularly use condoms. "I'm still scared, but I'm trying to fight with it," she says.

Niteen and Kavita's situation does not reflect the typical dilemma faced by the many HIV-infected people here who have no access to expert care, suffer from stigma, and understand little about the disease. But that's the point: India thrives on contradictions and diversity, mocking any description of its travails that holds too fast to one perception. As Johns Hopkins's Bollinger puts it, "India lives in 5 centuries at the same time."

Not only do Niteen and Kavita challenge the stock image of AIDS in India, they also have joined a cutting-edge clinical trial that

demonstrates how research has moved beyond describing the virus and its patterns of spread to more complex analyses. As part of an international study sponsored by NIH, NARI will evaluate whether treatment with antiretrovirals can lower the risk of HIV transmission in "discordant" couples such as Niteen and Kavita.

NARI is also conducting one of the world's largest trials to assess whether extended treatment of infants with the anti-HIV drug nevirapine can reduce transmission through breast milk, as well as a trial of a vaginal microbicide. NARI also plans to launch India's first AIDS vaccine trial in collaboration with the International AIDS Vaccine Initiative (IAVI). The small study of a vaccine that stitches HIV genes into a harmless adeno-associated virus should begin in the next few months, says IAVI's Jean-Louis Excler.

Outside NARI, both YRG CARE and the Tuberculosis Research Centre in Chennai have intensive hunts under way for cheaper ways to monitor the health of people receiving antiretrovirals. IAVI, which bankrolls another project to develop an Indian-made AIDS vaccine that uses modified vaccinia Ankara to shuttle in the HIV genes, hopes to stage full-scale efficacy trials, too, and Excler already has traveled extensively to evaluate possible sites. More than 100 Indian researchers also have trained at HIV/AIDS programs run by Johns Hopkins and UCLA, and all but a handful have returned home.

Looking ahead, forecasters see contradictions aplenty. "Ten years from now, I'm sure India will be at the top in terms of burden of disease and the magnitude of the problem," says Piot of UNAIDS. "But I'm also quite confident that India, at least in some of the states, will have the best AIDS programs in the world."

The stakes reach far beyond India's borders, contends the Global Fund's Feachem. "India is the single most important country with regard to the history of the global epidemic," says Feachem. "If we lose the fight in India, we lose the fight globally." **–JON COHEN**

TIMELINE OF HIV/AIDS IN INDIA

HIV In India—A Fast Spreading Epidemic

1986: First case of HIV detected in Chennai

1990: HIV levels among High Risk Groups like Sex workers and STD clinic attendants in Maharashtra and amongst Injecting Drug Users in Manipur reaches over 5 percent.

1994: HIV no longer restricted to high risk groups in Maharashtra, but spreading into the general population. HIV also spreading to the states of Gujarat and Tamil Nadu where high risk groups have over 5 percent HIV prevalence.

1998: Rapid HIV spread in the four large southern states, not only in high risk groups but also in the general population where it has reached over 1 percent. Infection rate among antenatal women reaches 3.3 in Namakkal in Tamil Nadu and 5.3 in Churachandpur in Manipur. Among IDUs in Churachandpur it crosses 76 percent and in Mumbai, 64.4 percent.

1999: The infection rate in antenatal women in Namakkal rises to 6.5. About 60 per cent of the sex workers in some Mumbai sites are infected. Infection rates among STD patients have reached up to 30 percent in Andhra Pradesh and 14-60 per cent in Maharashtra. About 64.4 percent IDUs at one of the sites in Mumbai and 68.4 percent in Churachandpur are infected.

2001: Infection crosses one per cent in six states. These states account for 75 per cent of the country's estimated HIV cases.

2002: An increase of about 6 lakh infections (4.58 million). The increase has been noticed primarily in states of Karnataka, Rajasthan, West Bengal, Tamil Nadu, Gujarat, Madhya Pradesh and Rajasthan. There is no significant increase in HIV infections in the country. India continues to be in the category of low prevalence countries with overall prevalence of less than 1 percent.

2003: A drop in the increase of infections. An increase of about 5.12 lakh infections as compared to increase of 6.1 lakhs infections last year. This shows that while the epidemic is still spreading in the country, there is no significant upsurge in the number of new infections. This is evident from the fact that during 2003 round of HIV sentinel surveillance, none of the States has moved from the category of low prevalence State to either medium or high prevalence categories.

2004: The estimated number of HIV infections for the year 2004 is **5.134 million.** Government claims there are only 28,000 added infections in 2004. In absolute numbers, India continues to stand second next to South Africa having 5.3 million HIV infections. In terms of prevalence percentage, India has HIV prevalence of 0.91% among adult population as compared to 21.5 % in South Africa.

HIV/AIDS in India

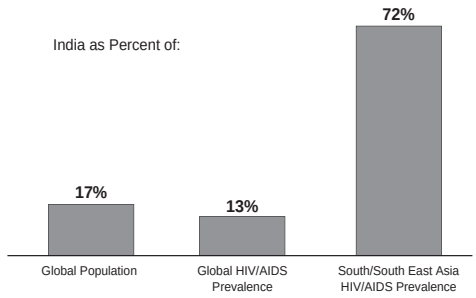
September 2005

With more than 5 million people estimated to be living with HIV/AIDS, India's HIV/AIDS prevalence is second in the world only to South Africa.[1,2] India is considered to be a "next wave" country; that is, it stands at a critical point in its epidemic, with HIV poised to spread quickly, but where large-scale prevention and other interventions today can help to avert a major epidemic in the future.[3] As the second most populous nation in the world[4], even a small increase in India's HIV/AIDS prevalence rate will represent a significant component of the world's HIV/AIDS burden.

Background [2,5,6,7,8]

- The first case of HIV disease was reported in India in 1986.
- Later that year, the Government of India established a National AIDS Control Committee under the Ministry of Health and Family Welfare to formulate a strategy for responding to HIV/AIDS in the country; it launched a National AIDS Control Programme in 1987.
- India's National AIDS Control Organization (NACO), established in 1992 by the Ministry with major support from the World Bank, is the implementing entity of the National AIDS Programme. Phase I of the Programme spanned 1992-1999. Phase II will span 1999-2006.
- NACO has facilitated the development of 38 State AIDS Control Societies (SACS), which operate in all states and Union Territories and in three cities.
- The Indian Government reports that it will provide 196 Crore (about $45 million) to Phase II of the National AIDS Programme, which is also supported by other donors.The government's overall HIV/AIDS budget for FY2004/2005 is estimated to be $69 million.

Figure 1: India as Percent of World Population and Global and Regional HIV/AIDS Prevalence, End 2004



Sources: NACO, 2005; UNAIDS, 2004; CIA World Fact Book, 2004.

Current National Estimates

NACO, the Joint United Nations Programme on HIV/AIDS (UNAIDS), and other international experts develop estimates of HIV prevalence (people living with the disease) and incidence (new HIV infections) in India:

- As of the end of 2004, there were an estimated 5.134 million people living with HIV/AIDS in India.[2]
- HIV/AIDS prevalence among adults[9] in India is still relatively low, at just below 1%.[2] Because of India's large population size, a small increase in prevalence represents a large number of people. Once a country's prevalence is greater than 1%, it is considered to have a "generalized epidemic" and HIV may spread rapidly.
- HIV/AIDS prevalence in India represents approximately 72% of HIV/AIDS prevalence in the South/South East Asian region, and 13% of global prevalence.[1,2] By comparison, India represents 17% of the world's population[4] (see Figure 1).
- Six Indian states are considered to have high HIV/AIDS prevalence (>1%) – Manipur, Nagaland, Andhra Pradesh, Tamil Nadu, Karnataka and Maharashtra – as are 49 districts within states.[2,5,6]
- Most HIV infections in India are due to sexual transmission (84-86%). In the North East, however, injection drug use is the main mode of transmission.[6,7]
- Women account for 39% of India's estimated HIV/AIDS prevalence[2]; HIV prevalence has been increasing among pregnant women in many regions within the country.[1]
- Among young people, ages 15-24, the estimated number of young women living with HIV/AIDS was almost twice that of young men.[10]
- Tuberculosis (TB) and HIV are intersecting epidemics. Those infected with HIV are more susceptible to TB infection, and TB may progress more quickly in those infected with HIV. TB is the most common opportunistic infection among people living with HIV in India.[2]

Key Trends

- NACO estimates that HIV/AIDS prevalence increased by 47% since 1998[2] (see Figure 2). Although these estimates indicate that new HIV infections in India do not seem to be on the rise, actual data on new HIV infections in India are not available. One way to approximate the number of new HIV infections in India is to apply India's share of the global total of people estimated to be living with HIV/AIDS (13%) to the global total of estimated new HIV infections (5 million), yielding an estimate that more than 600,000 Indians were newly infected with HIV last year.[1,2]
- India's share of people living with HIV/AIDS has grown as a proportion of global HIV/AIDS prevalence, rising from 11% at the end of 2001 to 13% at the end of 2004. Similarly, India's prevalence as a proportion of South/South East Asian prevalence rose from 67% to 72% over this period.[1,2]
- NACO also collects AIDS case surveillance data from SACS[2,7] but these data only provide a snapshot of the epidemic, given the delay in progression from HIV infection to an AIDS diagnosis and the large number of people living with HIV who do not know their status. This is the case in every country, including the United States.

Projections

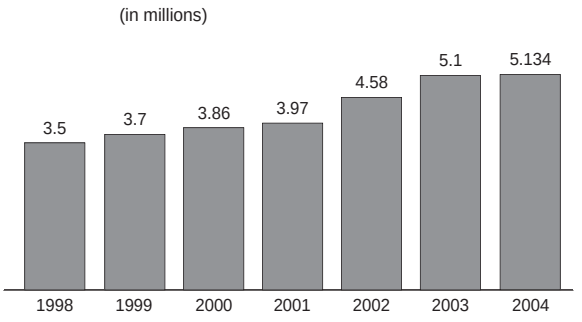
Several different projections have been developed to model the potential impact of the epidemic in India over time, including:

- *U.S. National Intelligence Council (NIC)*: A 2002 report by the NIC projected that by 2010, India could have 20 to 25 million people living with HIV/AIDS, the highest number of any country in the world.[11]
- *Eberstadt*: Researcher Nicholas Eberstadt of the American Enterprise Institute modeled several scenarios to project the epidemic's impact between 2000-2025. For example, he projects that life expectancy in India in 2025 could fall by 3-13 years, depending on epidemic severity.[12]
- *World Health Organization (WHO)*: The WHO estimated that HIV/AIDS caused 2% of all deaths and 6% of deaths due to infectious diseases in India in 1998. If current HIV/AIDS trends continue, by 2033, HIV could account for 17% of all deaths and 40% of

deaths from infectious disease.[13] The United Nations recently estimated that life expectancy gains in India are expected to be lower than they otherwise would be due to HIV/AIDS.[14]

- *World Bank*: A recent World Bank report examined alternate scenarios for expanding antiretroviral therapy in India, concluding that such an expansion is cost effective. However, without strengthened prevention efforts, the epidemic will not substantially slow.[13]

Figure 2: Number of People Estimated to Be Living with HIV/AIDS in India, 1998-2004



Sources: NACO, 2005; UNAIDS, July 2004.

HIV/AIDS Services/Activities

- *Support Groups and Networks*: As of 2003, there were 51 community care centers run by non governmental organizations (NGOs) in India. NACO supports 17 networks of people living with HIV/AIDS.[7]
- *HIV Counseling and Testing*: There were 722 voluntary counseling and testing (VCT) centers in India as of December 2004, most of which are supported by NACO through SACS. NACO and WHO established 3 model VCT sites in Chennai, Imphal and Mumbai.[7,15]
- *HIV Prevention:* The Indian Government and donors including the United States, the United Kingdom, the Bill and Melinda Gates Foundation (Gates Foundation) and others support a network of targeted interventions aimed at reducing transmission among those at highest risk.
- *Antiretroviral Therapy (ART)*: In 2003, the Indian Government announced its intention to provide free ART at government hospitals to people living with HIV/AIDS in the six high prevalence states and in the city of Delhi, beginning in April 2004. The WHO is procuring ARVs for the treatment roll-out. Eight government hospitals were selected for the initial launch (expected to increase to 25 in 2005).[7] As of April 2005, an estimated 35,000 people were receiving ARV therapy, including 7,333 people receiving treatment through the public sector. This represents about 5% of the estimated 770,000 adults in need of ART in India as of December 2004.[15]
- *Public Education Initiatives*: The Heroes Project, a national initiative co-chaired by Richard Gere and Parmeshwar Godrej in partnership with the Kaiser Family Foundation and supported by a grant from the Gates Foundation's Avahan Initiative, works with a cross-section of Indian media and societal leaders on a coordinated HIV/AIDS campaign. Population Services International (PSI) has social marketing activities on HIV/AIDS that span 22 States and Union Territories as well as the national highway system in the southern states.[16] The BBC World Service Trust has a co-production partnership with NACO and Doordarshan, the government-supported broadcaster, on HIV/AIDS programming.[17] There are other national and regional efforts to work with media on HIV/AIDS, including journalism programs developed by the Kaiser Family Foundation and the Avahan Initiative.
- *Generic Drugs*: India is one of the key manufacturers of generic antiretroviral drugs in the world,[7] which are sold within India and in other countries, including those in sub-Saharan Africa. There is some concern that India's recent compliance with World Trade Organization requirements to protect product patents on medicines may drive up prices for generics.[18,19]
- *HIV Vaccine Trials*: The first Phase I clinical trial for an HIV vaccine recently began in India. Conducted by NACO, the Indian Council of Medical Research, and the International AIDS Vaccine Initiative (IAVI), the trial will take place at the National AIDS Research Institute in Pune.[20]

Major Donors/Other Support

- The U.S. Government provides bilateral assistance to India for HIV/AIDS, and support through its contributions to the Global Fund. USAID has supported activities in India since 1995[21] and the CDC since 2001.[22] India is not one of the 15 focus countries of the President's Emergency Plan for AIDS Relief (PEPFAR), but has been identified as a country of "concern outside of the focus countries".[23] U.S. bilateral aid for India was $36 million in FY 2004, the largest outside of the 15 focus countries.[24]
- The United Kingdom, Australian, and Canadian governments also provide donor aid to India.[7]
- The Global Fund has approved the following grants in India:[25]
  - HIV/AIDS Round 2 (signed): $100,081,000 requested; two year funding of $26,116,000 approved.
  - HIV/AIDS Round 4 (one component signed): $140,878,119 requested; two year funding of $25,831,024 approved.
  - HIV/TB Round 3 (signed): $14,819,773 requested; two year funding of $2,667,346 approved.
- The World Bank has been a main financier of NACO, providing $84 million for Phase I of the National AIDS Programme and $191 million for Phase II.[26]
- UNAIDS, WHO, UNICEF, UNDP, and the other UNAIDS co-sponsors provide technical assistance and other support, through in country offices and partnerships.
- The Gates Foundation has committed $200 million through its Avahan Initiative.[27]

References

1 UNAIDS, AIDS Epidemic Update, December 2004.
2 NACO: www.nacoonline.org.
3 CSIS, *India at the Crossroads: Confronting the HIV/AIDS Challenge A Report of the CSIS HIV/AIDS Delegation to India*, 2004.
4 CIA, *World Fact Book*, 2004.
5 UNAIDS India Country Page: www.unaids.org/en/geographical+area/by+country/india.asp.
6 UNAIDS India: www.unaids.org.in.
7 NACO, *Annual Report 2002-2004*.
8 CSIS, Personal Communication, June 2005.
9 Ages 15-49.
10 UNAIDS, *Youth and HIV/AIDS: Opportunity in Crisis*, 2002.
11 U.S. NIC, *The Next Wave of HIV/AIDS: Nigeria, Ethiopia, Russia, India, and China*, 2002.
12 Eberstadt, N., "The Future of AIDS", *Foreign Affairs*, 2002.
13 The World Bank, *HIV/AIDS Treatment and Prevention in India: Modeling the Costs and Consequences*, 2004.
14 UN Population Division, *World Population Prospects, The 2004 Revision*, 2005.
15 WHO, "Summary Country Profile for HIV/AIDS Treatment Scale-Up: India", June 2005.
16 PSI: www.psi.org/where_we_work/india.html.
17 BBC: www.bbc.co.uk/worldservice/trust/pressreleases/story/2004/01/040119_doordarshanprojectextended.shtml.
18 MacNeil, D., "India Alters Law On Drug Patents", *NYT*, March 24, 2005.
19 Health Gap, *Fact Sheet: Changes to India's Patents Act and Access to Affordable Generic Medicines after January 1, 2005*.
20 NACO, *NACO News*, Vol. 2, February 2005.
21 USAID: www.usaid.gov/our_work/global_health/aids/Countries/ane/indianew.pdf,
22 CDC: www.cdc.gov/nchstp/od/gap/countries/india.htm.
23 U.S. Department of State, *Congressional Budget Justification, Foreign Operations, Fiscal Year 2006*.
24 U.S. Department of State, Office of the Global AIDS Coordinator, *Engendering Bold Leadership: The President's Emergency Plan for AIDS Relief First Annual Report to Congress*, March 2005.
25 The Global Fund: www.theglobalfund.org/search/portfolio.aspx?lang=en&countryID=IDA#HIV/AIDS.
26 The World Bank: www.worldbank.org.in/WBSITE/EXTERNAL/COUNTRIES/SOUTHASIAEXT/INDIAEXTN/
27 The Gates Foundation: www.gatesfoundation.org/GlobalHealth/Pri_Diseases/HIVAIDS/HIVProgramsPartnerships/Avahan.htm.

Prepared by Jennifer Kates and Alyssa Wilson Leggoe of the Kaiser Family Foundation (KFF). Additional copies of this publication (#7312-02) are available on the Kaiser Family Foundation's website at *www.kff.org*.

The Kaiser Family Foundation is a non-profit, private operating foundation dedicated to providing information and analysis on health care issues to policymakers, the media, the health care community, and the general public. The Foundation is not associated with Kaiser Permanente or Kaiser Industries.

ETHICS IN REPORTING ON HIV/AIDS

Setting Standards For Ethical Reporting On HIV/AIDS

By Mohuya Chaudhuri

It's now been over two decades since HIV/AIDS first surfaced in India. From being a completely unknown disease shrouded in mystery and dread, today a large proportion of the Indian population is well aware of the virus that causes AIDS. The media has played a crucial role in this dissemination of information. Newspapers—national and vernacular, the government-run television channel, Doordarshan, and the private networks have taken the message to the people through PSAs, news reports, investigative journalism and even through soaps or serials.

While all agree that the message has been delivered, some believe, reporting on HIV/AIDS has had its own pitfalls. Lack of proper guidelines within the media has caused several setbacks in the communication of HIV/AIDS. Several tragic incidents reveal instances where the media ended up increasing discrimination and perpetuating stereotypes instead of busting them. These cases have now forced many health journalists and even editorial teams in news organisations in India to review the need for universal reporting guidelines for HIV/AIDS.

Like any other emerging disease, HI V too was followed relentlessly by the media in the initial years. There was a novelty attached to writing or reporting on an issue that was so intimately linked with death and tragedy. In this pursuit, ethics was often given the short-shrift since the story had to be sensational. The first reports on the disease revolved around certain high-risk groups—sex workers, the gay community and truck drivers. The data released by agencies did point to them as most vulnerable to the disease. But since they were "fringe" groups, such reporting ended up branding them—"them" vs "us". It was insinuated that somehow, these groups were responsible for getting infected because of their "immoral" lifestyle. This kind of reporting created panic around the disease and "victimised" these groups, who were shunned even more by civil society. It also led to a certain degree of complacency—that all those who didn't belong to these groups, were safe from HIV/AIDS. It was only later that we would learn that this confidence was highly misplaced.

Defining ethics

To be fair, many individual newspapers and newly set up TV channels did follow a general set of rules, especially related to identities. But many groups felt targeted—sex workers, truckers and the gay community. At NDTV, a story being offered by a cub reporter on the risks faced by the gay community was abruptly turned down at the news meeting. It was only later that we learnt it was a carefully considered decision as the story would only reinforce stereotypes. NDTV finally did stories on the discrimination faced by PLWHAs in the workforce. This expanded the scope of HIV/AIDS reporting. It was a small but valuable lesson.

But HIV reporting is a continuous challenge. For instance, how does a channel deal with the identities of those who have HIV/AIDS or their families and associates in interviews (especially on television), off-the-record conversations, photographs, and stories.? Guarding the privacy of these people and refraining from reporting confidential information, and above all, refraining from treating them as victims—are issues that confront us daily. And answers to these form the very basis for ethical, just, and constructive coverage of HIV/AIDS.

Like any kind of journalism, reporting on HIV/AIDS too must follow the same fundamental principles. It must be fair, accurate and objective. But like all health communication, there is an added tenet—sensitivity—since the lives of many people are involved. One stray comment or remark can jeopardise the safety of an entire family or even a community.

"My first tryst with HIV/AIDS was in early 2002. I received a phone call and the caller told me about the ordeal of a 50-year-old man, Ram Bahadur, who, after being diagnosed with the virus was unable to get himself treated for a urinary tract problem," says a young reporter while recounting some of her earlier experiences while covering HIV. He had been refused treatment by six major hospitals, including the All India Institute of Medical Sciences. It was only after the court intervened that he was admitted.

"Ram Bahadur had been through such acute discrimination and the agony of being abandoned that he decided to come out with his status and requested me to publish his story with a picture and his name. The story widely followed by other news organizations taught me many lessons. Though media has a very important role in preventing HIV/AIDS and in protecting the rights of people living with this virus, insensitive, incorrect or sensational reporting could lead to tragic consequences for a family. In this case, some newspapers published wrong versions of Ram Bahadur's story which infuriated the doctors," she says.

Even now, there are no formal guidelines of reporting in most Indian media and young reporters learn from their mistakes, often after witnessing tragic consequences of their stories. This is one area where stigma is bigger than the story. HIV/AIDS reporting is not only about getting a good story to highlight the issue but it is about highlighting the issue sensitively to protect the people involved."

Fundamental principles

Looking at various sources in Africa, where the disease is so widespread and the United States where it was first discovered and reported extensively and comparing it with the Indian experience, here are some basic tenets that journalists must follow

1) Tell the truth. It is imperative that the public gets to the truth because that is the media's primary mandate. This right should not be compromised.
2) Keep the public updated. Informing the public about the latest relevant and interesting developments helps to arm people
3) Keep the facts straight. Distortion of facts for the sake of sensation is unacceptable. This includes presenting all sides of the story. Omitting key information because it doesn't fit into your story is a breach of faith. Censorship of relevant information is unethical because it deprives the public of information needed to make well-informed decisions. For instance, the ongoing clinical trials for the AIDS vaccine have thrown open new debates—whether or not to highlight the role of volunteers or hide their identities ?. Whether or not, the trial is going to be successful?. Journalists must strive to explain as best they can and not speculate or even jump the gun and say that "here is the answer to the AIDS pandemic". It is best to work closely with researchers to avoid misreporting.

   In fact, a journalist must seek clarifications at all times. There are sets of data which can be read in different ways and a reporter must be sure which is the right way. The debate over numbers of PLWHA in India is one such contentious issue. While India (with its 5.1 million infected population) may be closing in to South Africa's 5.3 million, it must be remembered that India's population is much bigger. While nearly one third of SA's population are HIV+, less than 1% of the population is infected in India. While that is not to say that it isn't an epidemic, but it does give a different perspective to the problem. Also, a news story must be covered objectively; the journalist needs to remain emotionally detached from the event, and refrain from taking sides. The topic of AIDS "cures" and treatments, for example, demands particular scrutiny, and should be reported critically. When getting close or friendly with a source of information—either an individual or an institution—journalists need to pay particular attention to providing facts-based stories and objective portrayals.
4) Ensure that your source is authentic. Or else, more myths such as sharing of bathroom seats or kissing can cause HIV, will be created.

5) Identities should be disclosed only with permission. Even family members who are not infected must be asked if they want to come out. Journalists must respect an individual's right to privacy and human dignity.

6) When interviewing someone who is living with HIV/AIDS, it is crucial to be sensitive to his or her needs and perspectives. In fact, it may be helpful to prepare some questions for the interview and to ask someone from a local HIV/AIDS service organization to comment on their appropriateness. It is also helpful to go over the questions with the source before the interview, or before the person agrees to the interview. Questions must be asked with care and tact. Don't probe into painful details for the sake of sensational "soundbytes" or even weeping on camera. Don't thrust mikes into faces of bereaved people. It is important to treat them with compassion.

7) Conversations should only be taped if the source gives explicit permission and only when the source is fully aware of it. No hidden cameras should be used. Confidentiality must be maintained. Information that was shared in confidence must not be reported. Incidents of people with HIV/AIDS being ostracized, persecuted, and even murdered after their identities and HIV status were made public are widespread.

Careless reporting can cost lives

In Upper Assam, an HIV positive child was asked to leave school after a local television channel carried a report on the child and his family. The family was then hounded out of town. In another case of an HIV positive woman, this time in Lower Assam, local villagers attacked and almost killed her after they got to know her identity. Families of HIV positive people are often driven out of their homes, especially in rural areas. There are many cases, where PLWHA have to live near burial grounds and even burning ghats because they are society's new "untouchables". Violence against HIV positive people is on the rise. While there have been several reports of people being tied up in cattle sheds and forced to live with animals with little food and no care, now it's gone a step further. In an Andhra village, a HIV positive widow, whose husband had died of AIDS as well, was nearly buried alive. Villagers didn't want to wait till she breathed her last. Few want to touch the bodies of those who died of AIDS.

Even in big metros, the situation is no different. Despite the awareness and access to treatment, counselling and care, many people are choosing to kill themselves, unable to bear the discrimination. In two months alone, three HIV positive patients who were undergoing treatment for HIV in a leading hospital killed themselves, forcing authorities to post guards outside wards where HIV positive people were being treated In such a barbaric climate, callously revealing the identity of HIV positive people can be dangerous.

8) All sources must be protected. Many times, a person speaks freely for the sake of some good. Say there's corruption in the disbursal of funds in an AIDS agency. But if his/her identity is revealed, then it puts the person in the dock, causing harm. This also means that information related to HIV/AIDS must be collected honestly and not illicitly. Say when a source shares information with the journalist with the understanding that it was simply part of a personal conversation, this information should remain private unless the source gives the journalist express permission to use it in a story. Often when TV stations demand authentication of any new data (sources say is usually not acceptable in TV), a journalist may be tempted to give out a name to guard their own end. But such a step would not only jeopardise the source but also kill a key avenue of information.

9) Take no favours from any agency, except data. Only the media organization for which the journalist works should compensate the journalist for covering stories. Accepting payment from interested parties creates a conflict of interest for the journalist and undermines the credibility of the news story.

10) Journalists should not expect, request, or accept payment for attending meetings, workshops, or conferences; the expectation of an allowance should not be the factor that motivates a journalist to attend such forums.

Look within

The media is playing a crucial and active role in raising the public's awareness about HIV/AIDS and health journalists stand on the frontlines of this fight. As with anyone dealing with a difficult issue, the first step is to examine one's own feelings, fears, vulnerabilities, and biases about the issue. This is imperative for journalists, whose personal sentiments and beliefs may strongly influence how they approach and report a story. For instance, if a journalist has reservations about sex workers or the gay community, these biases will reflect in the story unless one steps back.

By reporting stories that promote prevention of the virus and reduce the stigma associated with those suffering from it. Journalists who understand the public policy implications and the medical facts of HIV/AIDS and who are aware of the myths surrounding the disease will produce better stories. These stories will hold governments and communities accountable for their programmes, educate the public about prevention, offer methods for coping with the disease, and discredit stereotypes surrounding HIV/AIDS.

—Mohuya Chaudhuri is the News City Editor for NDTV

—Inputs from Toufiq Rashid, principal correspondent for The Indian Express

A Reporter's Journey: Some Real Life Issues Of Covering HIV/AIDS

By Kalpana Jain

The flight to Delhi from Imphal was delayed. Insurgency brought with it a host of problems and among them was a scarcity of almost everything. That afternoon, fuel was not available for the onward journey of the aircraft. As the airport security checked and re-checked our baggage—right from a pen to a hairbrush—an odd mix of passengers, tired of the seemingly endless wait, tried to engage in a conversation; if only to overcome their boredom.

This wasn't a place where people came for a holiday. Almost everyone present here was on business—a Chinese girl married to an Indian, trying to bring health and educational facilities to underdeveloped areas, a filmmaker, a school teacher and an NGO worker. At the far end of the lounge a young Manipuri man, dressed in a brown leather jacket and blue jeans was engaged in an animated conversation with his friend.

There was little that set him apart from the others. Only those who knew him closely were aware how quickly his life had changed in the past few years. The complex political, economic and social troubles of the state had created just the right conditions for a rapid entry of the human immune deficiency virus or HIV. Young injecting drug users, some still in school, had been caught unawares. Easy availability of heroin in this state was a perfect foil for a generation suffering from lack of jobs and a mood of despair.

Lilabanta, an architect by profession, had been among those who had suddenly woken up to a rude reality of being HIV positive. With the help of the positive people's network, he learnt to get back to living and helping others do so as well. At the airport, he was waiting for the flight to Calcutta to attend a meeting for positive people; from there he would leave for Delhi for another meeting.

Lately, AIDS is getting to be as much about living as it has been about dying. In fact, a year of looking closely at the HIV/AIDS epidemic lifted some of the gloom that I had felt while interacting with young, positive people earlier. These young people are changing the face of HIV infection. Gone are the earlier images of gloom and despair. Positive peoples' groups are leading in bringing about changes in perceptions to the epidemic and society's response to it. Collectives such as widows' groups, unheard of sometime back, are helping in strengthening the morale of their members as well as that of others with HIV.

It's not that I began my journey with this optimism or that I could sustain feelings of hope when I saw young widows, orphaned children and lonely grandparents. Or, the sight of old women, who barely had the strength to stand, back to ploughing the fields after losing the young, able-bodied members of their family to HIV. The death and sickness that I saw sometimes overwhelmed me. For instance, when I went to the Bel Air hospital and sanatorium at Panchgani to see the extent of spread around Mumbai, it seemed as though men, women and children were simply waiting for life to end. None of them could be addressed as `People Living With HIV'. I could not call them by any other phrase except `HIV Victims.'

As I saw more of the epidemic, it became clear that there are really two groups of people as of now—one, who are living with the virus and the other who are not being allowed a decent death or even burial. Even now, stories of acute discrimination abound. People who die of diseases brought on by AIDS, at times, are not even allowed burial space; people with HIV are moved to garbage dumps to die; children with HIV are not allowed to come to school. More recently, there was a bizarre case of a couple murdering an adopted

child after they suspected him of being HIV positive. Despite an abundance of such stories that reflect ignorance and fear of HIV, much has changed since the virus came into India. And much more can change if the media were to go about its job in an active and responsible manner.

When I started this work, like many others, I considered HIV distant. I must confess I too believed it was largely a disease of the promiscuous. Gradually, it occurred to me that I had created a false division in my mind of ``them'' versus ``us''. I realized that my middle-class attitudes and years of conditioning of what was right and wrong was making me talk to people living with HIV as an issue which was only theirs and couldn't happen to people like us. It is hard to accept that HIV is more about our lives and the complexities that decide our actions or that of our sexual partners.

During interviews with positive people, it almost became an unspoken condition that the route of transmission was not to be discussed. In fact, I felt that just asking this one question would seem judgmental on my part. It seemed to be so sensitive an issue with people living with the virus that I feared breaking a bond of trust that was building with those who were allowing me access into their very private spaces. Gradually I realized that people living with HIV are extremely sensitive to these moral judgements. Often, during interviews I would find people eager to explain how they had not got the virus through the sexual route.

Like most others, I also had to overcome my hesitations and fears of contracting HIV. Extending my hand to touch someone with HIV, did not reflect my deepest fears. These fears did surface within me when I first sat down to a meal at a meeting with the Maharashtra Network of Positive People. It meant sharing glasses and plates. It did need some self-counselling and rationalizing of my fears to join in. Of course, by the time we'd finished eating I had been baptized.

Tracking the hidden path of HIV required building bonds and trust and assuring people of complete confidentiality. It meant allaying suspicions and constantly having to explain that I had no other motive than to bring out the present situation of HIV/AIDS as a journalist.

In this journey of understanding AIDS, I also went through another journey: of seeing mankind at its worst and at its best. If I saw human dignity defiled and trampled on, I also met people who were willing to offer hope and help. If I saw corruption, I also came across real, genuine people. At the end of it all, the AIDS trail became a journey through life, through our social and economic realities and through our systems of governance and welfare. For me, AIDS reflects a very raw face of society.

(Lilabanta is no more. His memories live on in the optimism he instilled in those he came in contact with. With extracts from Positive Lives: The story of Ashok and others with HIV by Kalpana Jain, Penguin Books India 2002, ISBN 0-14-302817-0)

FREQUENTLY ASKED QUESTION ABOUT HIV/AIDS

What is HIV?
HIV stands for Human Immunodeficiency Virus. HIV destroys certain blood cells called CD4 or T cells. These cells are crucial to the normal function of the immune system which defends the body against illness. When the immune system has been compromised by HIV, a person typically develops a variety of cancers and viral, bacterial, parasitic, and fungal infections.

What is AIDS?
AIDS stands for Acquired Immunodeficiency Syndrome. It occurs when the immune system is weakened by HIV to the point where a person develops any number of diseases or cancers. A person without these diseases or cancers can still be diagnosed with AIDS if a laboratory test shows a severely damaged immune system.

How is HIV detected?
It is impossible to look at someone and know whether he or she is HIV-positive. The only sure way to determine this is through an HIV test. A blood sample can reveal the presence of the virus. If the blood sample contains HIV antibodies—proteins the body produces to fight off the infection—the person is HIV-positive.

How is HIV transmitted?
HIV is primarily transmitted through unprotected sex, including vaginal, anal and oral sex. Certain bodily fluids including blood, semen, vaginal secretions and breast milk spread HIV. The virus can also be transmitted through contaminated needles, which can happen when infected drug users share needles. An HIV-infected woman can pass the virus to her baby during pregnancy or breast-feeding. HIV is also transmitted through contaminated, unscreened blood supplies.

How is HIV not transmitted?
HIV is not an easy virus to pass from one person to another. The virus does not survive well outside the body. So, it cannot be transmitted through casual or everyday contact such as shaking hands or hugging. Sweat, tears, vomit, feces and urine do contain small amounts of HIV, but they have not been reported to transmit the disease. Mosquitoes and other insects do not transmit HIV.

How can HIV transmission be prevented?
The surest way to avoid transmission is to avoid identified high-risk behaviors. If that is not done, various health organizations have determined that; latex condoms can significantly reduce the risk of transmission; that pregnant women who are HIV-positive can reduce transmission to their children through HIV/AIDS antiretroviral treatment; and that intravenous drug users should not share needles.

How long does it take for HIV to become AIDS?
The length of time varies from person to person and depends a great deal on whether there is access to treatment. Generally, for those getting drug treatments, there can be a lapse of ten years or more for HIV to become AIDS. UNAIDS estimates that in countries where there is little or no access to treatment the period of time for the majority of people is eight to ten years.

What is the link between HIV and Tuberculosis?
HIV weakens the immune system and increases the likelihood of becoming infected with TB. An estimated one-third of all people living with HIV/AIDS worldwide are co-infected with TB and TB is one of the leading causes of death among those infected with HIV.

What is the link between HIV and Sexually Transmitted Diseases (STDs)?
People with a sexually transmitted disease are far more vulnerable than others to becoming infected with HIV. For example, genital ulcers caused by herpes create an entry point for HIV. STDs create concentrations of cells in the genital area that become targets for HIV. Also, HIV-positive people are far more vulnerable to acquiring additional sexually transmitted diseases than other people. Their immune systems are compromised which means the body has a more difficult time fighting off infection.

Is there a cure for HIV/AIDS?
There is no known cure for HIV/AIDS. There are medical treatments that can slow down the rate at which HIV weakens the immune system. There are other treatments that can prevent or cure some of the illnesses associated with AIDS. Researchers are testing a variety of vaccine candidates, but it is likely that a successful vaccine is years away.

How many people have HIV/AIDS?
The United Nations Joint Programme on AIDS (UNAIDS) estimates there are 39.4 million people worldwide living with HIV/AIDS. International scientists estimate that without stronger prevention measures, 45 million new cases of HIV/AIDS could occur by the year 2010.

What HIV/AIDS statistics are the most reliable?
UNAIDS provides the most extensive set of statistics related to the global epidemic at www.unaids.org. The statistics are compiled in consultation with country-level experts and international epidemiologists. Every country keeps count in its own way and some are more complete than others. (Read more in Frequently Asked Questions about Covering HIV/AIDS.)

What do endemic, epidemic, pandemic mean?
Endemic is the constant presence of a disease or infectious agent in a certain geographic area. Epidemic is the rapid spread of a disease in a certain area or among a certain population group. Pandemic is a worldwide epidemic; an epidemic occurring over a wide geographic area and affecting an exceptionally high proportion of the population.

What is ARV?
ARV stands for antiretroviral. It is a type of drug designed to slow the reproduction of HIV in the body. If ARV treatment is effective, the onset of AIDS can be delayed for years. It is recommended that ARV drugs be used in combination. You can find more details about specific drugs in the drug glossary.

What is HAART?
HAART stands for highly active antiretroviral therapy. It is the combination of at least three ARV drugs that attack different parts of HIV or stop the virus from entering blood cells. Even among people who respond well to HAART, the treatment does not eradicate HIV. The virus continues to reproduce but at a slower pace.

What is drug resistance?
Drug resistance is the ability of an organism (e.g. a virus, bacterium, parasite, or fungus) to adapt, grow and multiply even in the presence of drugs that usually kills it. It reduces the ability of ARV drugs to block the replication of HIV. In some people on HAART, HIV mutates into new strains that are highly resistant to current drugs.

What is ABC?
ABC stands for **a**bstinence, **b**eing faithful to a single partner and **c**ondom use. It is an approach to prevention that certain organizations and governments promote as a means to stop the spread of HIV.

What is the Global Fund?
The Global Fund to Fight AIDS, Tuberculosis and Malaria was created in 2001 at the urging of UN Secretary General Kofi Annan. The Global Fund is a partnership among governments, the private sector and affected communities. It is an independent grant-making organization whose purpose is to help developing countries fight AIDS, tuberculosis and malaria.

What is 3x5?
The WHO estimates that between US$ 289.9 million and US$ 307.2 million is required to support scaling up antiretroviral therapy to reach the WHO "3 by 5" treatment target of 3,55, 000 people by the end of 2005 for India. While national budgetary allocations for HIV/AIDS programs have increased over the years. The five-year budget of the National AIDS Control Programme increased from US$ 100 million for the first phase (1992–1997) to US$ 300 million in the second phase (1999–2006). But, of total government resources, an estimated US$ 85 million is expected to be committed for scaling up antiretroviral therapy during 2004–2005. By the end of April 2005, the government reported that 7,333 people were receiving free antiretroviral therapy through the public sector. The government plans to provide treatment in 188 centres across the country by 2007.

FREQUENTLY ASKED QUESTIONS ON COVERING HIV/AIDS

Is there really a difference between reporting that someone has AIDS or is HIV-positive?
Yes, there can be a difference. HIV-positive means someone is infected with the virus. It is possible an HIV-positive person will not be showing any symptoms and may or may not have progressed to an AIDS diagnosis. Someone who has AIDS has a severely weakened immune system. It is better to be specific about the stage of illness.

Who do I turn to for the most reliable numbers related to the epidemic?
There is a great deal of controversy and confusion about HIV/AIDS statistics. It is a very tricky exercise to find statistics that are meaningful and relevant because of the methodological difficulty to assessing estimates and actual numbers. Before using any, be absolutely certain you understand what they mean, who collected them, how they were collected and over what period of time. If you find numbers that contradict each other go back to your sources and ask them to explain the contradiction.

How important is confidentiality in reporting on HIV/AIDS?
Confidentiality means not publishing the name or photograph of an individual with HIV without their permission. The informed consent of the person should mean that he/she is aware of the risks of such exposure. At times, such consent is given only to newspapers/periodicals or channels that have no reach or circulation in areas where families, partners and friends of these people live. In such cases, people living with HIV should be made to fully understand the consequences of any media reporting.

Mediapersons need to be careful even when non government organizations present people living with HIV at conferences and say that they are willing to be interviewed. In one such case, media reported the story of two women, along with their names, who had apparently given their consent to the NGO. However, it was only later when these women faced serious stigma in their homes that the media realized that these women were only vulnerable pawns in the hands of the NGO. They did as they were told and did not realize the consequences on their lives.

What are the common stereotypes that slip into HIV/AIDS reporting?
The HIV/AIDS population is diverse and your reporting should reflect that. The goal, of course, is to be objective and factual. Stay away from making value judgments. A common stereotype involves what types of people become infected. High-risk behavior (e.g. unprotected sex, sex with multiple partners, and injected drug use) is certainly a significant factor. But, there is also a complex array of factors, including social and economic circumstances that cause vulnerability to HIV infection. Another common stereotype is to assume that if someone is in a high-risk population group, he or she is very likely to become infected. This is not necessarily true. For example, many men who have sex with men practice safer sex and have a single partner. So, they are not at a significantly greater risk than the general population.

What words do I want to be cautious about using in the context of HIV/AIDS?
Refer to the list that we have assembled. But, in general, do not use words that incorrectly stereotype people with HIV/AIDS, perpetuate myths about the disease or carry value judgments. Do not use terminology that general audiences cannot easily understand. This is especially important when reporting on medical stories. The goal is to be precise without being so dense your audience will not understand what you are reporting.

What are the pitfalls when reporting on treatments for HIV/AIDS?
HIV/AIDS treatment is a complex area and there are many different treatments available for HIV/AIDS – some treat the virus itself, others treat the symptoms and illnesses caused by the virus. However, none is a cure. It is easy to confuse a cure for a disease related to HIV infection, as opposed to a cure for HIV/AIDS itself. It is also easy to describe the drugs used to slow the growth of the virus as a cure. Again, there is no cure. There are human vaccine trials underway to seek a cure for HIV.

What are the pitfalls when reporting on alternative therapies for HIV/AIDS?
There is no cure for HIV. As a result people seek any form of medicine that claims to help them. Across the country, any number of people are coming up with these unethical claims. To be able to get these ``cures'', poor people with HIV do not hesitate in mortgaging their homes or selling off their meager belongings. Often these so called cures are expensive. Some of these cures may also lead to medical complications. The media should resist claims of such cures. It should take comments from top experts and carefully look into the merits and demerits of carrying a story when a claim seems promising.

Controversies on the origin of HIV tend to make news. How does one report them?
Mediapersons need to be aware that any incorrect information could have potentially serious consequences for several lives. While writing on controversies such as HIV does not lead to AIDS or that AIDS is a direct result of poverty, media persons need to give a complete and balanced picture so that people do not start taking such statements as valid, scientifically proven facts. In fact, every effort should be made to debunk various myths that surround HIV/AIDS.

Is it accurate to say that someone died of AIDS?
AIDS is a syndrome that can be defined by any number of diseases and cancers. There is no singular disease that is called AIDS. When someone, who had been diagnosed with AIDS does die, it is technically more accurate to report that he or she "died of an AIDS-related illness," of HIV-related causes, or due to HIV disease.

SENSITIVE LANGUAGE

The following table includes a list of language to be sensitive to when reporting on HIV/AIDS. It is intended to aid in an understanding of the complexities of reporting on HIV. In some cases, you may want to consider an alternative word or phrase. In others, you may end up using language that could be considered sensitive. The important thing is to be aware of the issues that surround these terms and their usage.

SENSITIVE LANGUAGE	WHY	ALTERNATIVES
AIDS/ HIV carrier	This is a stigmatizing term, which focuses on an individual as a carrier of disease. It is important to emphasize that HIV/AIDS is a disease that can be managed and lived with, rather than focusing on the diseased status of the individual.	HIV-positive, Person/ man/ woman living with HIV
AIDS Orphan	This term may stigmatize the child and the child's condition and may also misinterpreted to mean that the child is HIV-positive. The child may not be HIV positive but may have lost one or both parents due to HIV.	Orphans, Children affected by HIV/AIDS
AIDS sufferers/ victims	These words evoke images of helplessness and weakness.	People living with HIV/AIDS
AIDS test	The test determines the presence of HIV antibodies; therefore it tests for HIV infection, not AIDS. The progression to AIDS is the last stage of HIV disease.	HIV (antibody) test
AIDS virus	The correct name of the virus is HIV. AIDS is a syndrome caused by HIV.	HIV, The virus that causes AIDS
Body fluids	This phrase is very broad and can refer to a range of body fluids, not all of which can transmit HIV. It is always better to be specific.	Specify the fluids (e.g., blood)
"Catch AIDS"	HIV is transmitted (e.g. Sexually; mother-to-child, via blood), and then leads to the development of AIDS. Unlike contagious diseases, HIV cannot be "caught." Clarification HIV is not a contagious disease, i.e. it cannot be transmitted through casual contact (e.g. Sneezing, coughing, saliva).	Contract HIV Become infected with HIV, become HIV-positive
"Died of AIDS"	While this is frequently used, AIDS is actually a syndrome that can be defined by many different diseases. HIV gradually weakens a person's immune system and leads to one or more of many illnesses (opportunistic infections), which signal the progression to AIDS. These illnesses are the eventual cause of death.	"Died of an AIDS-related illness" "Died of an HIV-related illness"
Drugs for AIDS	This may be misinterpreted as meaning that there are cures for HIV/AIDS. It is important to clarify that while there are drugs to treat the symptoms, prevent and treat opportunistic infections and slow the progression of the disease, they cannot completely rid the body of the virus.	Anti-HIV therapy, AIDS-related drugs, Drugs to prevent and treat opportunistic infections (OI)
Full-blown AIDS	This is an older slang term that is rarely used anymore. Progression to AIDS is one stage of HIV disease.	AIDS

SENSITIVE LANGUAGE	WHY	ALTERNATIVES
Gay/ homosexual/ bisexual	These terms, particularly gay and bisexual, refer to an identity that may or may not be tied to a behavior. In many countries and cultures, men who have sex with other men may not perceive themselves as gay, bisexual, or homosexual. It is important to distinguish between behavior (which can place an individual at increased risk of transmitting and acquiring HIV) and sexual identity, particularly when talking about HIV transmission.	Men who have sex with men (MSM)
HIV and AIDS, HIV or AIDS	They are not two diseases. Rather, they are different stages of HIV disease.	HIV/AIDS, HIV disease
HIV-infected person	"HIV-positive" is preferable to "HIV-infected," as the latter term places emphasis on the infection, rather than the individual living with it	Living with HIV, HIV-positive, (Having) contracted HIV
HIV virus	This term is redundant. HIV stands for "Human Immunodeficiency Virus"	HIV
Innocent (victim), Guilty	This infers that certain modes of transmission are worse than others and that some HIV-positive individuals deserve their status.	Omit the word
Promiscuous	This term is based on the perception of an individual's behavior. It places a negative connotation on an individual who may look a certain way, have or be perceived to have more than one sexual partner and does not accurately reflect the social context of transmission. For example, an individual may be in a polygamous marriage, which is socially and religiously acceptable in many societies. It is important not to use language that judges others behaviors or is based on misconceptions or stereotypes.	This is a value judgment that should be avoided
Prostitute	This term has a negative connotation. It does not accurately describe situations in which women may be forced into exchanging sex for money or food due to gender inequality and lack of alternative economic opportunity.	Sex worker, Commercial sex worker
Risk group vs. Risk behavior	The phrase "risk group" may be interpreted as referring to the only people who are at-risk of contracting HIV. Individuals who do not belong to these groups may gain a false sense of security from infection. Additionally, individuals in a "risk group" may not practice risky behavior. An example of this is an injection drug user who uses clean needles that are not shared.	Risky behavior
Safe sex	There is always an inherent risk when having sex.	Safer sex
Scourge, plague, dreaded disease	These words are overly dramatic and over used. They also may imply judgment and it may be better to substitute with less dramatic language such as medical terms.	Disease, Epidemic, Illness
Sufferer, Victim	These terms imply passiveness and helplessness.	Avoid using these terms
Suspected (of having HIV), admitted (to having HIV)	These terms may foster stigma because they imply secrecy.	Avoid using these terms

REFERENCES

Beamish, J. *Reporting on HIV/AIDS: A Manual*. African Women's Media Center, UNDP, 2002 http://www.awmc.com/pub/p-4680/e-4681/

Foreman M. "An ethical guide to reporting HIV/AIDS." In Boafo, STK, Arnaldo, CA (eds.). *Media & HIV/AIDS in East and Southern Africa: A resource book*. UNESCO, 2000, http://www.unesco.org/webworld/publications/media_aids/index.html

Soul City and Health-e. (2003) *HIV/AIDS: A Resource for Journalists*, http://www.soulcity.org.za/downloads/final_Aids_Booklet.pdf

Made, P. *Gender, HIV/AIDS and Rights: A Training Manual for the Media*. Inter Press Service, 2002, http://www.ipsnews.net/aids_2002/ipsgender2003.pdf

Journalists Against AIDS Nigeria and United Nations Information Center. (2001) *Media Handbook on HIV/AIDS in Nigeria*.

UNDP. (1992) *HIV-Related Language Policy,* http://www.undp.org/hiv/policies/langpole.htm

ISSUES IN PRE-MARITAL TESTING

Pre-Marital Testing For HIV: Is It An Effective Tool For Checking The Spread?

Can a policy of pre-marital testing for HIV become an effective tool for checking the spread of the infection?. In some of the high prevalence areas, parents of prospective brides and grooms have started demanded such certificates. In the past, legislators in Goa and Andhra Pradesh have favoured the policy of making HIV testing mandatory before marriage.

Experience from other countries where such testing has been enforced and an objective assessment of such a policy shows otherwise. An American Civil Liberties Union report of March 1998 states, ``Rather than requiring that people seeking marriage licenses be tested for HIV, states should focus on education, for example, providing marriage applicants with AIDS education materials. Education should emphasise the importance of prevention and voluntary testing."

The HIV/AIDS Unit of Lawyers Collective believes that such a proposal will have a deleterious impact on India's efforts to contain HIV/AIDS. The Unit holds the view that such a proposal is based neither on sound public health nor human rights vision.

The view of Lawyers Collective is based on the following reasoning:

- The most common method of testing for the presence of HIV is an antibody test. However, at least for six months following the entry of the virus into a person's body, antibodies do not develop. This is known as the window period. A person may test negative for HIV during this period even though s/he is infected with the virus. In the absence of confirmatory and conclusive results, a person will end up infecting the spouse despite undergoing compulsory testing prior to marriage.

- Such a policy would only give a false sense of security and a false belief that the infection is being effectively prevented from spreading.

- A pre marital HIV mandatory test does not prevent persons from acquiring and transmitting infection after marriage.

- Mandatory testing would only drive the disease underground. Not many persons are aware of HIV, the nature of disease, its testing methods, routes of transmission. Due to ignorance most people are afraid of getting an HIV test done.

- Instead of checking the infection, it would compel people to travel outside the particular state where such a policy is in force to marry.

- It undermines individual's right to consent and confidentiality. Given that marriage is a social affair in most communities, the HIV status of the prospective bride and groom will become public subjecting the individual and family to stigma and ostracism.

- It could open a racket of issuance of false certificates prior to marriage.

- In most personal laws marriages are not required to be registered. Thus, for example, a Hindu marriage can be solemnized only by performing ceremonies. No registration is required. So a policy of mandatory testing would be impossible to implement.

- Such a policy will not empower women to negotiate sexual relations. It does not give women any information about HIV or about safe sexual practice.

The American Civil Liberties Union Report of March 1998 reported that mandatory pre-marital HIV testing was a record of failure. It stated that more than 30 states in the US considered pre-marital HIV testing. However, all the states, except for Illinois and Louisiana rejected the idea. Illinois and Louisiana enacted and enforced mandatory pre-marital testing but subsequently repealed them. In Utah too, a state in the United States of America, there was a legislation making a marriage to an HIV positive person void. However, the legislation in Utah was reversed as it was against public policy and they amended the same making such marriages valid.

Closer home, premarital testing has been in force in the State of Johar in Malaysia. Experts, however admit that the policy has been a failure. At the recently concluded 7th International Congress on AIDS in Asia and the Pacific in Kobe, physicians from Malaysia commented that singling out HIV/AIDS for pre marital testing has contributed to stigma while having zero impact on the number of new infections. (see http://www.healthdev.org/eforums/cms/individual.asp?sid=143&sname=ICAAP-17)

ANTI-RETROVIRAL DRUGS IN INDIA

Anti-retroviral Drugs In India Current Status, Issues And Challenges

By Pallava Bagla and Subhadra Menon

"We can't afford to lose any more community leaders without providing access to life saving antiretrovirals. We have no excuse for not providing antiretrovirals in India as we manufacture them in various brands and proudly export them to the whole world." —The Indian Network of Positive People, Chennai, Tamil Nadu

BACKGROUND

In the 22 years since HIV was first discovered in humans and identified as a communicable, viral infection, several medications have been formulated and put into use. The onset of full-blown AIDS after HIV infection can be delayed, not completely avoided. With no effective vaccine against the infection as yet—anti-retroviral drugs (ARVs) that can lower the viral load in the infected person, help in improving the quality of life and prolonging its span.

ARVs are still expensive for most Indians. Several nations across the world are trying to create systems and devise policies that can allow people free or subsidised access to these drugs. But these policies have obviously been easier to craft than to implement on the ground. While ingenious methods have been thought out and put into action to overcome the exorbitant costs of these drugs, the recent enforcement of the global Trade-Related Aspects of Intellectual Property Rights (TRIPS) agreement has forced countries like India to amend their patent laws.

The cost of ARVs is not the only challenge. ARVs are by nature potent drugs that can cause several side effects, something that affects the ability of patients to tolerate these drugs over the long-term (for they must be consumed life-long). Suffering too many side effects, patients often become defaulters of the punishing and expensive drug regimen, thus encouraging the creation of drug resistance. Director of the National Aids Research Institute, Pune, Ramesh Paranjape, says in India, despite the low usage of the drugs, signs of ARV resistance in the HIV virus are emerging.

The Indian government has, through the National AIDS Control Organization (NACO), New Delhi, been trying to streamline a free-ARV rollout across selected centres in the country since the middle of 2004. It aims at reaching 25,000 patients by the end of 2005. NACO's is an ambitious plan and one fraught with challenges—of fair access to the needy, infrastructural issues, immature management of medication and trying to keep pace with an ever-growing need. It is also a plan made difficult in its implementation by sheer numbers. Despite heated debates and strident protests over how many Indians actually suffer from HIV infection or AIDS, numbers are an integral part of this plan. There are estimates that in the coming 15–20 years, there will be anywhere between 200,000 to 490,000 Indians reaching out to the health sector for HIV/AIDS related services, care, treatment and support.[1] According to the World Health Organisation (2004) there are at least 600,000 Indians who currently need ARVs as treatment for HIV/AIDS.

[1] Over, M, Heywood, P. et. al. HIV/AIDS Treatment and Prevention in India: Modeling the Cost and Consequences. The World Bank, 2004

BASIC FACTS ABOUT ARVs

For some years from the time HIV/AIDS was discovered, patients were only given drugs to treat the many opportunistic infections (OIs) brought on by HIV's gradual assault on the immune system. Anti-HIV medication or ARVs were a late 1980s breakthrough—the first time that drugs could be actually used to reduce the ability of the virus to replicate and spread (i.e. slow down disease progression), and also to try and resuscitate the immune system. The decision of when to start a patient on ARVs is often an individual, case-based one, but technically, patients showing CD4 counts below 200 per milli-cubic meter are eligible for ARVs.

ARVs belong to five different classes of drugs.[2] The first are nucleoside reverse transcriptase inhibitors, the oldest known are ARVs such as AZT and abacavir. These act by disrupting the process of transcription (conversion of viral RNA to DNA so as to take charge of the human cell it infects). The second class of ARVs is non-nucleoside reverse transcriptase inhibitors (the commonly used nevirapine is from this class of drugs) They act by targeting the chemical that converts the viral RNA into DNA. Protease inhibitors such as indinavir and lopinavir affect the formation of new HIV particles. The fourth class of drugs is nucleotide analogues that interfere with some key enzymes required for viral replication of HIV. Tenofovir is an example of this class. The last and the most recently discovered class of ARVs are entry inhibitors—and as the name suggests they block the very entry of HIV into a CD4—Helper T cell.

When a patient begins to consume ARVs, the basic idea is to ensure that there must be a reduction in the viral load within the body and an increase in the CD 4 cell count. Infectiousness is highest soon after infection when an HIV-positive person shows a rapid growth in blood viral load. In most generalised cases, there is an average of 10 years between infection and death—it takes roughly five years from infection to the first showing of Opportunistic Infections and then another five years to full-blown AIDS (OIs and cancers) and finally, death. From the initial practice of using single drugs or two drugs, the last several years have seen the advent of combination drug therapy that can be efficient in suppressing HIV for many years. Once on effective ARV treatment, a person's life span can be doubled from what it would be without ARVs. The use of ARVs world over has slowly shown impact, in overall AIDS-related mortality figures.

Combination ARV therapy was discovered in the mid to late 1990s when it was found that using three or more ARV drugs in a combination, with a protease inhibitor thrown in, was much more effective than using them singly or in twos. This way, drugs show their effect for a longer time. Highly Active Antiretroviral Therapy (HAART) is another name for combination therapy. This kind of usage of mixed drugs is also helpful in delaying the development of drug resistance in the virus. It must be noted though that several patients are unable to tolerate combination therapy.

SIDE EFFECTS and DRUG RESISTANCE

ARVs are known to have several side effects, but as it is with most other drugs for diseases, the range and intensity of side effects varies from individual to individual. Some side effects of ARVs are easy to cope with, such as fever, headache and diarrhoea. There are the more chronic and troublesome side-effects—pancreatitis, peripheral neuropathy and skin rashes—that can even lead a patient to defaulting on the drug regimen.

[2] Barnes, Tracey, 2003. A Rough Guide to HIV. How's That Publishing Ltd, Great Britain.

This letting go of the consumption of drugs in what is a life-long regimen is creating drug resistance in HIV. Drug resistance can be the result of mutations within HIV that make the virus resistant to mainline drugs and while a certain degree of mutation is natural, it is a situation exacerbated by drug regimen defaulters. Therefore ARVs are available as first and second line of treatment regimens.

GENERIC DRUGS AND REDUCTION OF COSTS

Playing a big role in enhancing access to ARVs was the generic drugs manufacture initiated by Indian pharma companies in 2000, resulting in a dramatic reduction in the cost of the otherwise expensive drugs. Expert analyses are showing that the cost of ARVs has dropped to less than a dollar a day (not exactly cheap by Indian standards, but nevertheless cheaper than what ARVs were costing till not so long ago). There was a time when ARVs were not even available in India, and they could cost upto $ 20,000 per person annually in the developed countries where they were available. With generic versions from Indian and Brazilian pharma firms, the cost has come down to $240 per person per year, to less than a dollar a day per person.[3] Today, an average Indian may spend roughly Rs 1000.00 to Rs 1200.00 a month on ARVs, if it is the first line of drugs being used for treatment.

Moving to the second line is a costly option. The cost of second line goes up anywhere between four to six times over the first line of drugs, sometimes even up to 12 times, and according to WHO most second line drugs are still under patent, making access to them an issue in India. Often, within three to five years of treatment with first line ARVs, patients start to show resistance and required second-line therapy. In the richer countries of the world, where access and affordability are minor issues, several people are switching to the second and third line of ARV treatment when the first line of drugs ceases to be effective.

The new TRIPS compliant patents regime in India is expected to have lasting impact on the issue of access, especially to the second line and third line of ARVs. India has had the advantage of having companies like Cipla and Ranbaxy and it is their innovative manufacturing and marketing that allowed for building access to drugs for AIDS. Domestic manufacture of generic versions of ARVs in India will certainly be affected by the new regime, although it may be early days to actually evaluate the quantum of this impact.

THE CHALLENGES AHEAD

There are several challenges before India—for one it needs a rational policy for ARV usage and administration. This policy has to unfold under the realisation that ARVs are not a total cure, are expensive, and have a complex method of action that makes their administration a complicated and often bothersome issue. ARVs are administered in India in what is called "an unstructured method", one that does not conform either to WHO or NACO guidelines.

There is also the challenge of being able to assess the positive and negative effects of growing ARV use—a lower viral load in community would be a clear positive while greater drug resistance would be a negative. With more and more people on ARVs it is hoped there will be positive impact on the number of new infections arising in the community. Interestingly, the availability of ARVs is also known to strengthen prevention efforts.

There is a need to build much stronger networks for Voluntary Counselling and Testing (VCT) so as to ensure patients' early entry into ARV regimens. Counselling is also essential to counter any complacency that may set in within civil society regarding the need to protect oneself from HIV because of a growing availability and positive impact of ARVs.

[3] Over, M, Heywood, P. et.al. HIV/AIDS Treatment and Prevention in India: Modelling the Cost and Consequences. The World Bank, 2004.

It would be vital, once having accepted the need to stay abreast with the best of treatment options for HIV, for India to keep pace with the latest research on drug resistance by targeting a wider range of mechanisms within HIV replication as possible ways for anti-HIV medication to act.

One overarching challenge that HIV/AIDS faces is the stigma and discrimination that is part and parcel of this epidemic. It must be understood that any amount of progress and betterment within the sector of HIV/AIDS treatment will be futile without a lessening of social discrimination against patients of HIV/AIDS besides their immediate families and communities.

* * *

(Key words: CD4—T Helper Cells; Viral Load; Combination Therapy; "3 by 5' Initiative; Drug Resistance)

—Pallava Bagla is the chief correspondent in South Asia for Science Magazine
—Subhadra Menon is a health and science writer and author of "No Place to Go: Stories of Hope and Despair from India's Ailing Health Sector" (published 2004 by Penguin Books)

DRUGS AVAILABLE IN INDIA

1. Reverse transcriptase inhibitors

    i. Nucleoside analogue
    - AZT (azidothymidine, zidovudine) - 100 mg. each tablet
    - DDC (zalcitadine) - 75 mg. Tablet each
    - Stavudine - 100 mg. Tablet each
    - Lamivudine - 150 mg. Tablet each

    ii. Non-nucleoside analogue
    - Nevirapine - 200 mg. Tablet each

2. Protease inhibitors

    i. Saquinavir

    ii. Ritonavir

    iii. Indinavir

(VI) Post exposure prophylaxis

The following drugs are only used for post exposure prophylaxis and supported by the Government of India

- Zidovudine - 300 mg. twice daily for 4 weeks
- Lamivudine - 150 mg. twice daily for a period of 4 weeks
- Indinavir - 800mg. Thrice daily (only when indicated as part of expanded regime)

SOURCE: National AIDS Control Organization (NACO), 2004

For a complete list of the US Federal Drug Administration's (FDA) approved anti-retroviral drugs, please see page 46.

Public Hospitals in India That Provide Antiretroviral Therapy, 2004–05

At the start of the ARV rollout in mid 2004, drugs were made available at the following centres:

1. Sir JJ Hospital, Mumbai, Maharashtra
2. Institute of Thoracic Medicine and Chest Diseases, Tambaram, Chennai
3. Regional Institute of Medical Sciences (RIMS), Imphal, Manipur
4. Bangalore Medical College Hospital, Bangalore, Karnataka
5. Osmania Medical College Hospital, Hyderabad, Andhra Pradesh
6. Ram Manohar Lohia (RML) Hospital, New Delhi
7. LNJP Hospital, New Delhi
8. District Naga Hospital, Kohima, Nagaland

According to NACO, these eight centers have achieved "an adherence rate of 96.1% among people who have been placed on treatment." The first drug procurements were made by WHO.

During 2004-05, this list was expanded to include 17 more hospitals. It is expected that the total 25 hospitals will meet the government target of providing ART to 25,000 patients. These hospitals are:

1. Madras Medical College, Chennai, Tamil Nadu
2. District Hospital, Nammakal, Tamil Nadu
3. Government Medical College, Madurai, Tamil Nadu
4. Government Medical College, Vizag, Andhra Pradesh
5. Government Medical College, Guntur, Andhra Pradesh
6. Government Medical College, Sangli, Maharashtra
7. B J Medical College, Pune, Maharashtra
8. Government Medical College, Nagpur, Maharashtra
9. Karnataka Medical College, Hubli, Karnataka
10. Mysore Medical College, Mysore, Karnataka
11. Jawaharlal Nehru Hospital, Imphal, Manipur
12. Government Medical College, Ahmedabad, Gujarat
13. Government Medical College, Panaji, Goa
14. PGIMER, Chandigarh, Punjab
15. Calcutta Medical College, Kolkatta
16. SMS Hospital, Jaipur, Rajasthan
17. Banaras Institute of Medical Sciences, Varanasi

Source: The Government's Stance (NACO Annual Report, 2002–2004)

FREQUENTLY ASKED QUESTIONS ON PATENTS

Q. What is a Patent?
A. A patent is a limited monopoly given to an individual or corporations for a limited number of years for technological inventions in a particular territory, ordinarily a country. It is granted at the request of individuals/ corporations by the Patent Office in the respective country. Hence, a patent is available within the territory of the granting countries. Nearly 97 per cent of world's patents belong to developed countries.

Broadly patents can be classified into process patent and product patent. A process patent grants a monopoly on the process of manufacturing of a product and not on the product itself. However, with a process patent it is always possible to make the product through another process. Therefore a process patent confers only a limited monopoly. On the other hand, a product patent gives a monopoly on the product itself and prevents others from manufacturing, selling, distributing and importing that patented product without the authorization of the patent holder. No other person can produce that product. Thus a complete monopoly results which leads to high prices and puts the patented drug out of reach of majority of people, especially in developing countries such as India.

Q What is the impact of product patent on access to treatment?
A. It is important to remember that competition leads to lowering of prices and lack of it to high prices. When a product patent is granted by the patent controller to a single manufacturer, it creates a complete monopoly in that product or drug. As a result, there is no competition. This leads to high prices. This affects consumers and compromises accessibility and availability. Example: Anti retroviral drugs.

Q What is the justification for patent?
A. It is a supposed reward for disclosing the invention to the public. It is supposed to induce investment in research and development and advancement of science and technology.

Q. What are the main provisions of the Patents Act, 1970 vis-à-vis drugs?
A. Earlier the Act did not protect product patents at all for drugs. It protected only the process of manufacture of the drugs, that is process patents. The period of patent protection was for a period of seven years. Through a process of reverse engineering, generic version of new drugs could be legally produced.

It recognized compulsory licensing: a license granted by the state to commercially exploit a patented product or process during the protected period on grounds of (a) public requirement not satisfied (b) high pricing.

The government could import patented drugs in India for its own use or for distribution in hospitals and medical institutions.

Q. What amendments were brought to the 1970 Patent Act in March 2005 and why?
A. The amendments were made because of the TRIPS (Trade Related Aspects of Intellectual Property Rights) agreement. India signed TRIPS agreement which came into force on 1.1.2005.
The latest amendment, the third amendment, was passed by Parliament in March 2005. Previous amendments in 1999 and 2002 have already implemented TRIPS obligations. The only requirement vis-à-vis the third amendment was substitution of Exclusive Manufacturing Rights with product patents.

Q. Which drugs will be affected?
A. Two categories of drugs will be affected—one, drug inventions after January 1, 2005 and two, drugs that have been patent protected outside of India after January 1, 1995. In the first case, if a medicine is patentable,

the patent holder will be granted a 20-year monopoly from the date of filing. Generic versions of the drug will not be permitted on the market for the life of the patent unless a compulsory license is granted.

India's patent law has been changed to include the second category of drugs. To include these drugs, India was required to set up a ``mailbox'' under TRIPS in which patent applications between 1995 and 2005 could be filed. Over the past ten years, only a few hundred new chemical entities (NCEs) have been identified, whereas approximately 4,000 patent applications for medicines are in India's mailbox. Experts estimate that most of those patent applications are for already known medicines with only slight modifications. With such patenting the patent applicant try to extend the life of the patent, known as ever-greening. This blocks generic drugs from entering the market and pushing prices down.

Q. What is Compulsory licensing and its implications?
A. To prevent the owners of medicines under patent from abusing their monopoly position, patent law all over the world allows other drug manufacturers to make the drug. That can happen in two ways: one, with the consent and agreement of the patent holder, voluntary licensing or two, without the consent, agreement or authorization of the patent holder, that is, compulsory licensing. The license in this case is issued by the government under the Patent law. Compulsory licensing is resorted to by the government when production of the medicine by the owner does not meet the demand, or the price of the medicine is too high.

In both cases the licensee has to pay patent holder compensation or royalty which can be fixed in law or arrived at by agreement etc. The sum under royalty should not be more than four to five per cent of the total sales that will be made from the person requesting to make the medicine.

However, under the law passed by the government, compulsory licensing can be resorted to by the government only after three years from grant of a patent. In addition, the person making the request has to go through many bureaucratic processes and wait a further six months after the initial three years before the request will be dealt with by the patent office. Added to this, patent holders have been known to demand very high royalties before giving permission which leads to legal wranglings and long delays.

Q. What are the concerns over rule making powers?
A. The Act as amended confers too much power to the Patent Office.

Q. What are the other concerns?
A. The 2002 amendment removed the ceiling of four per cent royalty given to multinational companies for generic production under a compulsory license or for production for non-commercial use by the government. The 2005 Act simply states, `reasonable royalty' which leaves it ambiguous and allows multi nationals to decide on the royalty amount. In the past multi nationas have demanded royalties as high as 25 per cent which would have an impact on the price of generic drugs produced.

Q What will be the impact of changes in India's patent Act on access to AIDS drugs in poor countries?
A. New patent monopolies in India will drive up the cost of medicines for treatment of AIDS as well as several other public health problems such as cancer, diabetes and heart disease to name a few in the medium and long term. This cost increases will burden poor people in India as well as in importing countries around the world. In the case of HIV treatment, people who develop resistance to the first line of treatment will find it difficult to go in for the second line which is 21 times more expensive.

Answers by Lawyers Collective

IMPORTANT TERMS IN ANTIRETROVIRAL THERAPY

TERM	DESCRIPTION
Antiretroviral Therapy (ART or ARV)	ART (or ARV) refers to any of a range of treatments that include antiretroviral medications. These drugs are designed to destroy retroviruses, such as HIV, or interfere with their ability to replicate. The four classes of antiretroviral drugs currently available are nucleoside reverse transcriptase inhibitors (NRTI), non-nucleoside reverse transcriptase inhibitors (NNRTI), protease inhibitors (PI) and fusion inhibitors. The drugs on the following pages are all antiretrovirals.
Combination Therapy	The use of two or more antiretrovirals in combination.
Food and Drug Administration (FDA)	The U.S. Department of Health and Human Services' agency responsible for ensuring the safety and effectiveness of all drugs, biologics, vaccines and medical devices, including those used in the diagnosis, treatment and prevention of HIV infection, AIDS and AIDS-related opportunistic infections. The FDA also works with the blood-banking industry to safeguard the nation's blood supply.
Fusion Inhibitor	Fusion Inhibitors are a class of ART that work by blocking HIV from entering target cells and preventing it from multiplying, since HIV needs to be inside the cells to make copies of itself.
Generic Name	A drug that is identical, or bioequivalent, to a brand name drug in dosage, safety, strength, how it is taken, quality, performance, and intended use. The generic name of a drug is the common name of the drug and not protected under any manufacturer's copyright. It is the more commonly used format when referring to a drug in medical literature or the media. Generic also refers to less-expensive, but chemically identical, medications manufactured by companies that did not invent the drug. In some countries, generic drugs come on the market after a patent on the drug has expired. In other countries, generic drugs are manufactured and sold even before a patent expires.
HAART (Highly Active Antiretroviral Therapy)	Refers to ARV treatment regimens that act aggressively to suppress the replication of HIV and progression of HIV disease. The usual HAART regimen involves the use of three or more antiretrovirals.
Nucleoside Reverse Transcriptase Inhibitor (NRTI)	Nucleoside Reverse Transcriptase Inhibitors are a class of ART that block the replication of HIV by interfering with Reverse Transcriptase (RT), a protein that HIV needs to make more copies of itself.
Non-Nucleoside Reverse Transcriptase Inhibitor (NNRTI)	Non-nucleoside Reverse Transcriptase Inhibitors are a class of ART that block the replication of HIV by interfering with Reverse Transcriptase, a protein that HIV needs to make more copies of itself. NNRTIs work in a slightly different way than NRTIs.
Protease Inhibitor (PI)	Protease Inhibitors are a class of ART that act by blocking the function of protease, a protein that HIV needs to make more copies of itself.
Trade Name	The trade name is the name designated by the drug manufacturer. The first letter of the trade name is capitalized.

FDA-APPROVED ANTIRETROVIRAL THERAPY

Generic Name	Pronunciation	Trade/Brand Name	Class	Date of FDA Approval	Description
Zidovudine, AZT, ZDV	zye-DOE-vue-deen	Retrovir	NRTI	Mar. 19 1987	Zidovudine, also known as AZT and ZDV, was the first drug approved for treatment of HIV in adults in 1987. In 1990, it was approved for use among children 3 months of age and older. In 1994, it became the first drug to be approved for use among HIV-positive pregnant women to prevent mother-to-child transmission (MTCT) of HIV during pregnancy and delivery. In such cases, it is also given to the baby during the first 6 weeks following birth. Zidovudine is available in capsule, tablet, syrup and intravenous forms.
Zalcitabine, ddC	zal-SITE-a-been	Hivid	NRTI	Jun. 19 1992	Zalcitabine, also known as ddC, was approved in 1992 for use in combination therapy for treatment of adults and pediatric patients. It is available in tablet form.
Stavudine, d4T	STAV-yoo-deen	Zerit	NRTI	Jun. 24 1994	Stavudine, also known as d4T, was approved in 1994 for treatment of HIV infection in adults, and in 1996 for pediatric use. It is available in liquid and capsule forms.
Lamivudine, 3TC	la-MI-vyoo-deen	Epivir	NRTI	Nov. 17 1995	Lamivudine, also known as 3TC, was approved in 1995 for use in combination therapy for adults and children over 3 months of age. It is available in liquid and tablet forms.
lamivudine/ zidovudine	la-MI-vyoo-deen, zye-DOE-vue-deen	Combivir	NRTI	Sep. 27 1997	Combivir is the combination of zidovudine and lamivudine in a single tablet. Also known as 3TC/ADV, Combivir was approved in 1997 for use by adults and adolescents over 12 years of age.
Abacavir	a-BAK-a-vir	Ziagen	NRTI	Dec. 17 1998	Abacavir, also known as ABC and abacavir sulfate, was approved in 1998 for use in combination anti-HIV therapy among adults and children over 3 months of age. It is available in tablet and liquid forms.
Abacavir/ lamivudine/ zidovudine	a-BAK-a-vir, la-MI-vyoo-deen, zye-DOE-vyoo-deen	Trizivir	NRTI	Nov. 14 2000	This single tablet formulation of abacavir, lamivudine and zidovudine was created because these three drugs were frequently prescribed together. Trizivir was approved in 2000 for use in treatment of adults and teenagers weighing at least 88 pounds.
Didanosine, ddI	di-DAN-oe-seen	Videx	NRTI	Oct. 9 2001	Didanosine, also known as ddI, was approved in 1991 for use in adults and children over 6 months of age. It is available in capsule, tablet, liquid and powder forms.
Tenofovir	te-NOE-fo-veer	Viread	NRTI	Oct. 26 2001	Tenofovir, also known as TDF, BisPOC and PMPA, was approved in 2001 for use in combination therapy among adults. It is available in tablet form.

Generic Name	Pronunciation	Trade/Brand Name	Class	Date of FDA Approval	Description
Emtricitabine, FTC	em-trye-SYE-ta-been	Emtriva	NRTI	Jul. 2 2003	Emtricitabine, also known as FTC, was approved in 2003 for use in combination therapy among adults. It is available in capsule form.
nevirapine	ne-VYE-ra-peen	Viramune	NNRTI	Jun. 21 1996	Nevirapine, also known as Viramune and NVP, was the first FDA-approved non-nucleoside reverse transcriptase nhibitor (NNRTI). It was approved for use in adults and children over 2 months of age. It is also used to prevent mother-to-child transmission (MTCT) of HIV. NVP is available in tablet and liquid form.
Delavirdine, DLV	de-la-VIR-deen	Rescriptor	NNRTI	Apr. 4 1997	Delavirdine, also known as Rescriptor and DLV, was approved in 1997 for combination thearpy use among adults. It is available in tablet form.
Efavirenz	ef-FAH-ver-enz	Sustiva	NRTI	Sep. 17 1998	Efavirenz, also known as Sustiva, Stocrin and EFV, was approved in 1998 for use in adults and children over 3 years of age. It is available in capsule form.
Saquinavir	sa-KWIN-a-veer	Fortovase Invirase	PI	Invirase- Dec. 6 1995 Fortovase- Nov. 7 1997	This drug is available in two forms. Saquinavir, also known as Fortovase, was the first FDA-approved protease inhibitor (PI). It was approved for use in adults and children 16 years of age and older. Fortovase is the more commonly prescribed form and is available as a liquid-filled soft-gel capsule. Saquinavir mesylate, also known as Invirase, was approved in 1995 and was the first FDA-approved protease inhibitor (PI). It is available as a hard gelatin capsule and must always be taken with Ritonavir. Both are approved for use in combination therapy.
Ritonavir, ABT-538	rit-ON-uh-veer	Norvir	PI	Mar. 1 1996	Ritonavir, also known as Norvir, was approved in 1996 for combination therapy use among adults, and in 1997 for use among children 2 years of age or older. It is available in soft gel capsules and liquid form.
Indinavir, IDV	in-DIN-a-veer	Crixivan	PI	Mar. 13 1996	Indinavir, also known as Crixivan, was approved in 1996 for combination therapy use among adults. It is available in capsule form.
Nelfinavir, NFV	nel-FIN-a-veer	Viracept	PI	Mar. 14 1997	Nelfinavir mesylate, also known as Viracept, was approved in 1997 for combination therapy use among adults and children 2 years and older. It is also used to prevent infection in cases of accidental exposure and is available in tablet form.
amprenavir	am-PREN-a-veer	Agenerase	PI	Apr. 15 1999	Amprenavir, also known as Agenerase, was approved in 1999 for use in combination therapy among adults and children 4 years of age and older. It is available in soft gel capsule and oral solution forms.

Generic Name	Pronunciation	Trade/Brand Name	Class	Date of FDA Approval	Description
lopinavir/ ritonavir	Low-PIN-a-veer, ri-toe-na-veer	Kaletra	PI	Sep. 15 2000	The lopinavir and ritonavir combination, also known as Kaletra, was approved in 2000 for combination therapy use in adults and children 6 months of age and older. It is available in capsule and liquid forms.
Atazanavir	at-a-za-NA-veer	Reyataz	PI	Jun. 20 2003	Atazanir, also known as Reyataz, was approved in 2003 for combination therapy use in adults. It is available in capsule form. Atazanavir is different that the other protease inhibitors in that individuals who form resistance to it may still be able take other PIs.
fosamprenavir	FOS-am-pren-a-veer	Lexiva	PI	Oct. 20 2003	Fosamprenavir, also known as Lexiva or 908, was approved in 2003 for combination therapy use in adults and children 16 years of age and older. It is available in tablet form.
tipranavir	tip-ran-a-vir	Aptivus	PI	June 22 2005	Aptivus, manufactured by Boehringer Ingelheim, was approved for the treatment of HIV by the FDA in June 2005. Aptivus/ ritonavir is only approved for HIV-infected people who have tried and failed other anti-HIV drug regimens in the past. Aptivus must be used in combination with Norvir (ritonavir) and at least two other anti-HIV drugs.
Enfuvirtide, T-20	en-FYOO-vir-tide	Fuzeon	Fusion Inhibitor	Mar. 13 2003	Enfuvirtide, also known as Fuzeon or T-20, was approved in 2003 for combination therapy use in adults and children six years and older. It is available in injection form, administered as a shot under the skin.
Abacavir / lamivudine	a-BAK-a-vir, la-MI-vyoo-deen	Epzicom	NRTI	Aug. 2 2004	Epzicom, also known as abacavir and lamivudine, is a combination of two antiretroviral drugs: abacavir sulfate (Ziagen) and lamivudine (Epivir). Both of these drugs are nucleoside reverse transcriptase inhibitors (NRTIs). Epzicom was approved by the FDA on August 2, 2004, for treatment of HIV infection in adults. Epzicom should be used in combination with other types of anti-HIV drugs.
Tenofovir	te-NOE-fo-veer	Truvada	NRTI	Aug. 2 2004	Truvada includes two antiretroviral drugs: emtricitabine (Emtriva) and tenofovir disoproxil fumarate (Viread). Both of these drugs are nucleoside reverse transcriptase inhibitors (NRTIs). Truvada was approved by the FDA as a coformulation on August 2, 2004, for use with other antiretrovirals in the treatment of HIV-1 infection in adults.

This is a complete list of Antiretroviral Therapy approved by the US Federal Drug Administration as at October 2005. For a list of antiretroviral drugs available in India, see page 41.

REFERENCES

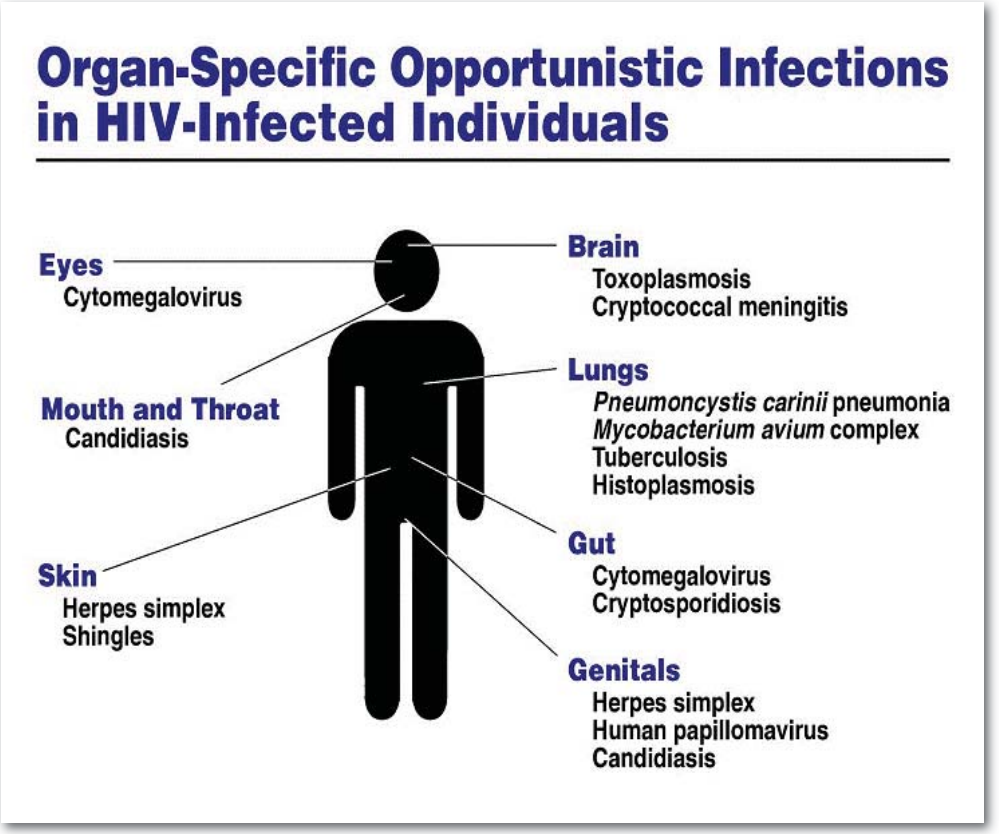
American Foundation for AIDS Research (amfAR). *Global Link: A Guide to International HIV/AIDS Research, Treatment, and Clinical Trials*. Vol. 2, No. 1 (Summer 2003), www.amfar.org/GlobalLink

Pieperl, L. & Coffey, S. *Overview of Antiretroviral Drugs*. HIV InSite. University of California San Francisco. 25 Nov. 2003, http://hivinsite.ucsf.edu/InSite.jsp?page=ar-drugs

U.S. Department of Health and Human Services (DHHS). *AIDSinfo Drug Database*, http://aidsinfo.nih.gov/drugs/

U.S. Food and Drug Administration (FDA). *Drugs Used in the Treatment of HIV Infection*. October 2003, http://www.fda.gov/oashi/aids/hiv.html

OPPORTUNISTIC INFECTIONS



Fauci, A.S. (2004, March 20) *HIV Therapies and Vaccines: Progress and Priorities*. Kaiser Family Foundation: AIDS in America: A Forgotten Epidemic? A Conference for News Leaders. Barbara Jordan Conference Center, Washington D.C.

GENERAL NOTES

- **Opportunistic Infections (OI)** are diseases that rarely occur in healthy people but cause infections in individuals whose immune systems are compromised as a result of HIV infection. These organisms are frequently present in the body but are generally kept under control by a healthy immune system. HIV gradually weakens a person's immune system and leads to the development of one or more opportunistic infections, which signals the progression to AIDS. These illnesses are the eventual cause of death. When a person dies as a result of an opportunistic infection, it is said that he/she died due to an HIV-related illness or AIDS-related illness, rather than died of AIDS.

- **Prophylaxis** refers to the prevention or protective treatment of disease. Primary prophylaxis refers to the medical treatment that is given to prevent onset of an infection. Secondary prophylaxis refers to medications given to prevent recurrent symptoms in an existing infection.

- **Antiretroviral therapy** refers to any of a range of treatments that include antiretroviral medications. These drugs are designed to destroy retroviruses such as HIV, or interfere with their ability to replicate. HAART (Highly Active Antiretroviral Treatment) refers to a course of treatment that involves the use of three or more antiretroviral drugs. HAART strengthens the immune system and therefore helps protect against opportunistic infections.

BRAIN

Cryptococcal Meningitis [krip-toe-KOK-kull men-in-JY-tiss] is caused by *Cryptococcus*, a fungus commonly found in soil contaminated by bird droppings. People become infected with *Cryptococcus* by breathing in dust that is contaminated with the fungus. Although most people have been exposed to this fungus, it does not usually cause disease in healthy individuals. Among people with HIV, infection most often results in meningitis. Symptoms may include fever, headache, nausea, vomiting, stiff neck, mental confusion, vision problems and coma. Cryptococcal meningitis does not spread from one person to another. Primary prophylaxis (treatment to prevent disease) and secondary prophylaxis (treatment to prevent disease recurrence) are available. The disease can be treated with anti-fungal medications. Without treatment, death can occur quite rapidly.

Toxoplasmosis [tock-so-plaz-MO-siss] (also referred to as Toxo) is an infection caused by a parasite found in cat feces, raw meat, raw vegetables and soil. Infection can result from eating contaminated food or contact with cat droppings. Toxo can infect many parts of the body but most commonly causes encephalitis, an infection of the brain. It cannot be spread from one person to another and does not cause infection among people with healthy immune systems. Symptoms may include fever, confusion, headache, personality changes, tremors and seizures, and can result in coma and death. Primary and secondary prophylaxes are available. Toxo can be treated with a combination of anti-toxo drugs.

EYES

Cytomegalovirus [sigh-TOE-meg-a-low-VY-rus] (also referred to as **CMV**) is a virus that typically causes an eye disease called **retinitis** [ret-tin-EYE-tis]. Retinitis is the most common type of CMV infection among people with HIV. CMV can be passed from person-to-person through saliva, semen, vaginal secretions, urine, breast milk and transfusions of infected blood. While anyone can be infected with CMV, illness occurs only among people with weakened immune systems. Symptoms may include blind spots and blurred, distorted or decreased vision that can progress to complete blindness. Primary prophylaxis may be recommended in certain cases. Forms of treatment for retinitis include intravenous medications, pills and injection of drugs directly into the eye. Secondary prophylaxis is also available. If left untreated, the disease will cause blindness.

MOUTH

Candidiasis [can-did-EYE-a-sis] is the most common fungal infection in people with HIV. It usually affects the mouth, throat, lungs and vagina (see *Genitals*). The fungi that cause Candidiasis are naturally present in the human body and are responsible for most cases of the disease, but rare cases of person-to-person transmission have been recorded. Although anyone can develop the disease, it is more common among people with HIV. Infection in the mouth is called *thrush,* and can cause pain when swallowing, nausea and loss of appetite. Symptoms of throat infection may include chest pain and difficulty swallowing. Primary prophylaxis is not recommended and use of secondary prophylaxis may be recommended in certain cases. There are a variety of treatments available to control infection.

SKIN

Herpes simplex [HER-peez SIM-plex] is a disease caused by the Herpes simplex virus. There are two types of Herpes simplex virus (HSV): HSV1, which causes cold sores or blisters around the mouth and the eyes; and HSV2, which causes genital or anal herpes. The viruses are spread from one person to another by contact with an infected area such as the mouth and genitals. Symptoms appear in outbreaks of rash, which may involve itching, tingling and the appearance of painful blisters or sores. HSV can affect anyone but outbreaks are more frequent and more serious in people with HIV. Although there is no prevention or cure for HSV, there are treatments that shorten the length and severity of the outbreaks.

Herpes zoster [HER-peez ZOS-turr], also known as **shingles**, is caused by the virus responsible for the chickenpox, Herpes Varicella-zoster virus. Although it can also affect HIV-negative individuals, it is most common among people with HIV because of their weakened immune systems. It results in very painful rashes and blisters on the chest, back and face. The rash typically affects one side of the body and lasts for a few weeks. There are no primary or secondary prophylaxes available for shingles. Treatments include anti-herpes drugs and pain medications.

INTESTINES / GUT

Cryptosporidiosis [krip-toe-spor-rid-ee-O-sis] (also referred to as Crypto) is an intestinal infection that is easily spread through contact with water, feces or food that have been contaminated with a common parasite called *Cryptosporidium*. Symptoms may include diarrhea, nausea, vomiting, weight loss and stomach cramps. Infection usually lasts one to two weeks in HIV-negative individuals, but can last much longer and be life threatening in people with HIV. While there are no medications that prevent or treat crypto, there are a variety of treatments to control the diarrhea caused by infection.

Cytomegalovirus [sigh-TOE-meg-a-low-VY-rus] (also referred to as CMV) is a virus that most commonly affects the eyes (see CMV retinitis), but among people with HIV it can also cause colitis [ko-LY-tis], which is an infection of the colon. CMV can be passed from person to person through saliva, semen, vaginal secretions, urine, breast milk and transfusions of infected blood. While anyone can be infected with CMV, illness occurs only among people with weakened immune systems. Symptoms of CMV colitis may include abdominal pain, diarrhea, cramps, weight loss and blood loss. Primary and secondary prophylaxes, and treatments are available.

GENITALS

Candidiasis [can-did-EYE-a-sis] is the most common fungal infection in people with HIV. It usually affects the vagina, mouth (see *Mouth)*, throat and lungs. The fungi that cause Candidiasis are naturally present in the human body and are responsible for most cases of the disease, but rare cases of person-to-person transmission have been recorded. Although anyone can develop the disease, it is more common among people with HIV. Symptoms of vaginal infection may include white discharge, itching, and pain during urination or sexual activity. Primary prophylaxis is not recommended and secondary prophylaxis may be recommended in certain cases. Anti-fungal treatments help control the fungus but recurrence of the infection is common.

Herpes simplex [HER-peez SIM-plex] is a disease caused by the Herpes simplex virus. There are two types of Herpes simplex virus (HSV): HSV1, which causes cold sores or blisters around the mouth and the eyes, and HSV2, which causes genital or anal herpes. The viruses are spread from one person to another by contact with an infected area such as the mouth and genitals. Symptoms appear in outbreaks of rash, which may involve itching, tingling and the appearance of painful blisters or sores. HSV can affect anyone but outbreaks are more frequent and more serious in people with HIV. Although there is no prevention or cure for HSV, there are treatments that shorten the length and severity of the outbreaks.

Human papillomavirus [pa-pill-LOW-muh-VY-rus] (also referred to as HPV) is a commonly occurring genital infection that is caused by a group of viruses called human papillomavirus. HPV is easily passed from person to person through direct contact with infected areas, for example during sexual activity. It can cause genital warts, which look like bumps on the penis, vagina and anus. Certain types of HPV are also linked to cervical cancer. The virus can be passed from one person to another even when a person is asymptomatic. Anyone can be infected with HPV but infection is usually short in healthy people. Among people with HIV, HPV infection is more serious, can recur frequently and last for long periods of time. Primary and secondary prophylaxes for HPV are not available. While there is no cure for HPV, there are numerous ways to remove warts and dysplasias.

LUNGS

Histoplasmosis [hiss-toe-plaz-MO-sis] is caused by a fungus found in soil contaminated with bird droppings or other organic matter. People get infected by breathing in dust that is contaminated with the fungus. Anyone can be infected with the fungus, but people with HIV are more likely to develop the disease. Symptoms may include fever, weight loss, fatigue, difficulty breathing and swollen lymph nodes. Histoplasmosis typically affects the lungs, but among people with weakened immune systems, the disease can spread to the rest of the body. That is a serious complication that can be fatal if left untreated. Histoplasmosis is not transmitted through person-to-person contact. Primary prophylaxis is not currently recommended. Anti-fungal medications are available for treatment of histoplasmosis and secondary prophylaxis is available to prevent disease recurrence.

***Mycobacterium avium* Complex** [MY-ko-back-TEER-ree-um A-vee-um] (also referred to as MAC) is an illness caused by *Mycobacterium avium* and *Mycobacterium intracellulare*. These two similar types of bacteria are commonly found in water, soil, dust and food. Anyone can be infected with the bacteria but HIV-infected individuals are at higher risk of developing serious disease. Disease symptoms may include fever, weight loss, night sweats and weakness. Infection can occur at one site in the body or can spread throughout the body. A variety of drugs are available to treat and prevent MAC.

***Pneumocystic carinii* pneumonia** [NEW-mo-SIS-tis CA-RIN- nee-eye new-MO-knee-yuh] (also referred to as PCP), now known as *Pneumocystis jiroveci* [yee-row-vet-zee] pneumonia, is caused by a fungus and usually appears as a lung infection. The fungus is believed to be spread through the air. Although it can be present in the lungs of any individual, it causes serious disease only when an infected individual's immune system becomes weakened. It is the most common opportunistic infection among people with HIV. Symptoms may include dry cough, chest tightness, fever and difficulty breathing. Although PCP is entirely preventable and treatable, it is a serious disease that can be fatal if untreated. There are a variety of drugs available for primary and secondary prophylaxis, and treatment of PCP.

Tuberculosis [too-burr-qu-LOW-siss] (also referred to as TB) is a common bacterial infection among people with HIV. An individual can become infected with TB when another person who has active TB coughs, sneezes or talks. Although TB also affects HIV-negative individuals, people with HIV are at higher risk of infection. While not all infected people become ill, TB infection speeds up HIV progression and is the leading cause of death among people with HIV worldwide. Symptoms may include fever, cough, night sweats, weight loss, fatigue, swollen lymph nodes and coughing up blood. Primary prophylaxis is available but secondary prophylaxis is not considered to be necessary. A variety of antibiotics are used in treatment of TB. Depending on the severity of infection, treatment can last for many months or even years.

KEY FIGURES

The list that follows is intended to give you a flavor of the depth and breadth of some of the key individuals involved in the HIV/AIDS pandemic and their fields of expertise. These are people from all over the world, involved in the medical, social, political, economic and cultural aspects of the crisis. Some were there at the beginning and others have more recently made their mark; some are current references and contacts while others have historical significance in understanding the epidemic. Where possible, we have provided website links which will lead you to more information about each individual and the organizations with which they are associated.

Lists such as these invariably leave some readers feeling frustrated. This one is not intended to be exhaustive and does not include many of those involved in HIV/AIDS, only some of the more notable individuals. We believe, however, those described below will provide you with a good overview of many who have made a difference.

Terje Anderson
Anderson also served on the U.S. Federal Health AIDS Advisory Committee from 1994 to 2003. The Committee provides HIV/AIDS policy information to the Secretary of Health and Human Services and the Assistant Secretary for Health. He was a member of the President's Advisory Council on HIV/AIDS from 1995–2002 and has worked in the field of HIV/AIDS for over 20 years. Anderson has been living with HIV/AIDS for many years.
(www.napwa.org)

Kofi Annan
Kofi Annan became the Secretary-General of the United Nations in 1997 and is currently serving a second term in office. He has advocated for increased global attention to HIV/AIDS and has described the epidemic as his "personal priority." In 2001, Annan convened the groundbreaking U.N. General Assembly Special Session on HIV/AIDS. He also issued a five-point "Call to Action," which led to the creation of the Global Fund to Fight AIDS, Tuberculosis and Malaria. In 2001, Annan was awarded the Nobel Peace Prize.
(www.un.org)

Bono
Bono is the lead singer of the Irish rock band U2 and has used his celebrity to draw the attention of politicians to the crises of HIV/AIDS and impoverished African nations. Bono has a long history of social involvement. In 2002, he co-founded DATA, which stands for Debt, AIDS, Trade, Africa. Through DATA, Bono lobbies wealthy governments to increase resources for Africa and forgive debt obligations so money can be directed to fighting AIDS and other social crises.
(www.data.org)

William Clinton
Bill Clinton served two terms as President of the United States from 1992 to 2000. In 2003, he announced the creation of the Clinton Foundation HIV/AIDS Initiative. One of the Initiative's greatest successes to date was to convince five generic drug companies to dramatically reduce the costs of commonly used antiretroviral drugs for people in developing countries. In 2002, at the International AIDS Conference in Barcelona, Mr. Clinton said "There are still people who view AIDS as something that affects only people who are different. We all know the victims."
(www.clintonpresidentialcenter.com)

Jerry Coovadia
Dr. Coovadia is Chair of HIV/AIDS Research at the Nelson Mandela School of Medicine at the University of Natal in Durban, South Africa. In 2000, he chaired the International AIDS Conference in Durban, South Africa. Dr. Coovadia was previously professor of pediatrics and child health, and has worked extensively on mother-to-child transmission of HIV through breastfeeding. At a public health conference in 2004 he cautioned, "We need to reinvent government to respond to public needs and the public health agenda."
(www.hivan.org.za)

Max Essex
Dr. Essex is chairman of the Harvard AIDS Institute and of the Department of Immunology and Infectious Diseases at the Harvard School of Public Health. He was among the first researchers to describe the transmission mechanisms of HIV, calling particular attention to the dangers of contaminated blood transfusions. His later research into the molecular identity and genetic variations of the virus has been critical to the development of HIV diagnostic tests and vaccine research. In 1985, Dr. Essex and colleagues established an AIDS research and training center in Dakar, Senegal.
(www.aids.harvard.edu/index.html)

Paul Farmer
Dr. Farmer is a physician and medical anthropologist, and is actively involved with HIV/AIDS in Haiti. He is well known for helping create innovative community-based approaches to treating HIV/AIDS and TB in resource-poor settings, particularly in Haiti. While a medical student in 1987, Farmer helped found Partners in Health, a community-based health project to support people with HIV and other infectious diseases. He has served as its executive director since 1991. Dr. Farmer also is an attending physician in infectious diseases, and chief of the Division of Social Medicine and Health Inequalities at the Brigham and Women's Hospital in Boston, Massachusetts. In 1993, Dr. Farmer received a MacArthur Foundation "genius" award.
(www.pih.org)

Anthony Fauci
Dr. Fauci is one of the longest-serving U.S. government officials helping to oversee HIV/AIDS research and one of the first scientists to begin studying HIV. In 1984, he became Director of the National Institute of Allergy and Infectious Diseases at the National Institutes of Health, which conducts extensive research to prevent, diagnose and treat infectious diseases, including HIV/AIDS. He serves as one of the key advisors to the White House and Department of Health and Human Services on global AIDS issues. Dr. Fauci has made numerous contributions to basic and clinical research in the field of immune-mediated illnesses.
(www.niaid.nih.gov/)

Richard Feachem
Dr. Feachem has worked in international health for over 30 years and in 2002 was appointed the first Executive Director of the Global Fund to Fight AIDS, Tuberculosis and Malaria. Upon accepting the position, Dr. Feachem said, "the Fund is positioned to make large investments in controlling these terrible diseases and improving the lives of millions of families throughout the world." Prior to joining the Global Fund, Dr. Feachem founded and directed the Institute for Global Health in San Francisco.
(www.theglobalfund.org)

Robert Gallo
Dr. Gallo is Director of the Institute of Human Virology at the University of Maryland Biotechnology Institute. In the early 1980's he discovered the human immunodeficiency virus that causes AIDS, a distinction he shares with Luc Montagnier of France, who also identified the same virus. Research by Dr. Gallo and his team also lead to the development of the HIV blood test. For a time, there was great controversy about whether Dr. Gallo stole the virus from Dr. Montagnier. Eventually U.S. and French health authorities agreed that both men should share the credit for discovery of HIV**.** In 2002, Dr. Gallo and Dr. Montagnier announced their partnership in the Program for International Viral Collaboration, an effort to advance global HIV/AIDS vaccine research.
(www.umbi.umd.edu)

William (Bill) Gates III
Gates is Chairman and chief software architect of the Microsoft Corporation and is also co-founder of the Bill and Melinda Gates Foundation. The Foundation committed US$ 500 million to global HIV/AIDS efforts through 2005. Since its inception in 2000, the Gates Foundation has committed billions of dollars towards improving global health overall, especially in the fields of HIV/AIDS & TB, infectious diseases, and reproductive and child health.
(www.gatesfoundation.org)

Helene Gayle
Dr. Gayle directs the HIV, TB and Reproductive Health Program at the Bill & Melinda Gates Foundation. She also is president of the International AIDS Society, which is responsible for coordinating the biennial International AIDS Conferences. Dr. Gayle co-chairs the Global HIV Prevention Working Group, an international panel of HIV/AIDS experts convened by the Gates and Kaiser Family Foundations. Prior to joining the Gates Foundation, she was Director of the National Center for HIV, STD and TB Prevention at the U.S. Centers for Disease Control and Prevention.
(www.gatesfoundation.org)

Richard Gere
Gere is an American actor and AIDS activist. His activism began in the United States with organizations such as the Elizabeth Glaser Pediatric AIDS Foundation. He has extended his HIV/AIDS work to India where he founded the Gere Foundation India Trust. The Gere Foundation, in coordination with the Kaiser Foundation Family and other organizations, launched a major public awareness campaign in India in 2004.
(www.gerefoundation.org)
(www.heroesprojectindia.org)

Elizabeth Glaser
Elizabeth Glaser was co-founder and Director of the Pediatric AIDS Foundation until her death in 1994. Glaser became an activist after she discovered she had received a contaminated blood transfusion in 1981 and had passed the virus on to her two children. After the death of her daughter due to HIV and frustrated by the lack of pediatric HIV/AIDS research, Glaser established the Foundation in 1988 to promote research and prevention of mother-to-child HIV transmission. The Foundation, which officially became the Elizabeth Glaser Pediatric AIDS Foundation after her death, is a leader in the effort to treat and prevent HIV/AIDS among children in developing countries.
(www.pedaids.org/)

Yusuf Hamied
Dr. Hamied is chairman of Cipla, an Indian pharmaceutical company. In 2001, Cipla announced its plans to sell generic AIDS combination therapies at vastly discounted prices, igniting widespread criticism from other pharmaceutical companies. The combination therapies consist of multiple antiretroviral medications combined into a single pill. Dr. Hamied announced that Cipla would sell these drugs for approximately US$ 350 per patient per year, compared to the previous price of over US$ 10,000 per patient per year.
(www.cipla.com)

David Ho
Dr. Ho is director of the Aaron Diamond AIDS Research Center in New York City and was named *TIME* Magazine's "Man of the Year" in 1996 for his groundbreaking AIDS research. As a medical resident in Los Angeles during the early 1980s, he saw some of the earliest cases of AIDS. Dr. Ho's subsequent research on HIV/AIDS led to the development of "AIDS cocktails," which consist of combinations of antiretroviral therapies. Combination therapy has resulted in a significant decline in AIDS-related deaths among people with access to treatment. Dr. Ho's current work includes the China AIDS Initiative, which teams with partners to develop treatment and care programs, mobilize leadership, educate the population and strengthen civil society groups involved with HIV/AIDS.
(www.adarc.org)
(www.chinaaidsintiative.org/)

Nkosi Johnson
Nkosi was a young South African whose bravery and suffering drew renewed international attention to the HIV/AIDS crisis. Nksoi was born HIV-positive and died of an AIDS-related illness in 2001 when he was just 13. A year earlier, Nksoi spoke at the International AIDS Conference in Durban telling a global audience, "Care for us and accept us, we are all human beings." He championed many causes during his short life, including human rights and providing care and shelter for people living with HIV/AIDS.
(www.nkosi.iafrica.com)

Jim Yong Kim
Dr. Kim is Director of the World Health Organization's Department of HIV/AIDS, where he leads the "3 by 5 Initiative" to provide antiretroviral therapy to three million people in developing countries by 2005. He is a renowned physician-anthropologist. Dr. Kim is a co-founder with Dr. Paul Farmer of Partners in Health, a non-profit organization operating in many of the world's poorest regions. Dr. Kim is also associated with Harvard Medical School and Brigham and Women's Hospital, both in Boston, Massachusetts. In 2003, he received a MacArthur Foundation "genius" award.
(www.who.org)
(www.pih.org)

Stephen Lewis
Lewis is the United Nations' Special Envoy for HIV/AIDS in Africa and is recognized as an especially articulate and passionate speaker, with a particular emphasis on children affected by AIDS. Lewis is also a director of the Stephen Lewis Foundation, which states as its goals; support for women dying of AIDS, the children left behind and NGO's assisting people living with AIDS. He previously served as Deputy Executive Director of the United Nations Children's Fund (UNICEF) and as Canadian Ambassador to the United Nations.
(www.stephenlewisfoundation.org)
(www.unaids.org)

Nelson Mandela
Mandela has become a strong voice in the global fight against HIV/AIDS after earlier being criticized for not urgently responding to the epidemic while President of South Africa. He created the 46664 Global Campaign to create more awareness, advocate for care and treatment and raise needed funds. In 2004, at the International AIDS Conference in Bangkok, he told delegates, "As former prisoner 46664, there is a special place in my heart for all those that are denied access to their basic human rights." He also has encouraged the public health community to pay more attention to the links between AIDS and tuberculosis.
(www.46664.tiscali.com)
(www.nelsonmandela.org)

Jonathan Mann
Mann was an inspirational and influential figure in the fight against global HIV/AIDS. The long-time researcher and human rights champion died in a plane crash in 1998, on his way to an AIDS conference. In 1986, he helped establish and lead the World Health Organization's Global Program on AIDS. In that role, he established human rights as central to the WHO's HIV/AIDS strategy and persuaded health ministers from dozens of countries to do the same. He is remembered for asking, "People say there is no use trying to change the world. But if we don't try, will it change?"
(www.doctorsoftheworld.org/about//about_details.cfm?QID=1327)

Thabo Mbeki
South African President Mbeki has been a controversial and polarizing figure in the fight against HIV/AIDS. In 1999, Mbeki declared that HIV, alone cannot lead to AIDS and he publicly questioned whether antiretroviral therapies for HIV are effective. By 2002, his government committed to intensifying prevention and treatment efforts. President Mbeki's pledge rested on the premise that HIV *does* cause AIDS. In 2005, Mbeki described South Africa's HIV/AIDS program as among "the best in the world."
(www.southafrica.info.)

Luc Montagnier
In 1983, Dr. Luc Montagnier of the Pasteur Institute in France discovered the virus that causes AIDS, the human immunodeficiency virus. It is a distinction he shares with Dr. Robert Gallo of the U.S. In 1986, Dr. Montagnier's team also identified HIV-2, the virus that is responsible for many HIV-infections in West Africa. Dr. Montagnier is currently president of the World Foundation for AIDS Research and Prevention. In 2002, Dr. Montagnier and Dr. Gallo announced their partnership in the Program for International Viral Collaboration, an effort to advance global HIV/AIDS vaccine research.
(www.pasteur.fr)

Yoweri Museveni
Ugandan President Museveni has led a successful campaign against HIV/AIDS in his country, which is held up as a model for the rest of Africa. Soon after assuming the presidency in 1986, Museveni became the first African leader to speak openly about the epidemic. His government's campaign is based on ABC, Abstinence, Be faithful, Condom use. There is much discussion over what has been the main driver of Uganda's success. Museveni is sometimes criticized by those who believe he minimizes the importance of condoms in the ABC program.
(www.government.go.ug)

Peter Piot
Dr. Piot was appointed the first Executive Director of UNAIDS in 1995. He coordinates the HIV/AIDS efforts of ten co-sponsoring organizations. Dr. Piot has longed worked in the public health arena. In 1976, he co-discovered the Ebola virus in Zaire. In the 1980's, he contributed to an understanding of the epidemic's spread in Africa. As Executive Director of UNAIDS he has said, "Investment in AIDS will be re-paid a thousand-fold in saved lives and communities held together."
(www.unaids.org)

Jeffrey Sachs
Professor Sachs, currently Director of the Earth Institute at Columbia University in New York, is one of the world's foremost economists. He is known for his work with governments and international agencies to promote poverty reduction, disease control and debt reduction for poor countries. He has urged poor nations to suspend debt payments to rich creditors and instead, use that money to fight HIV/AIDS and other social ills. Professor Sachs warns that AIDS is "exploding. Its consequences will make the world quake." Previously, he spent 20 years at Harvard University.
(www.earth.columbia.edu)

Paulo Teixeira
Dr. Teixeira previously was Director of the World Health Organization's (WHO) HIV/AIDS Department. He gained worldwide recognition for his work on HIV/AIDS in Brazil and Latin America. Dr. Teixeira was director of the National STD/AIDS Program at the Ministry of Health in Brazil, where he created the first national AIDS program in 1983. Dr. Teixeira pioneered Brazil's program for free, universal distribution of ARVs, which has become a model for other developing countries dealing with HIV/AIDS. He is now involved in environmental issues.
(www.who.int/hiv/en/)

Randall Tobias
Ambassador Tobias was selected by U.S. President Bush in 2003 to be the Administration's first Global AIDS Coordinator. In this role, he oversees all U.S. international HIV/AIDS assistance. Tobias has overseen a rapid scale up of US HIV/AIDS support and activities throughout the world. Prior to joining the Administration, Ambassador Tobias was President and CEO of the Eli Lilly pharmaceutical company. He and the Administration have been criticized by some who believe they place too much emphasis on abstinence as a means of preventing HIV/AIDS. In 2004, at the International AIDS Conference in Bangkok, he warned critics of the Administration's policies, "At this point, perhaps the most critical mistake we can make is to allow this pandemic to divide us."
(www.state.gov/s/gac)

Mechai Viravaidya
Mechai Viravaidya is a Senator in the Parliament of Thailand and is affectionately known as the "Condom King" because of his strong and public support for the use of condoms as a way of preventing HIV transmission. Senator Mechai is the founder and chairman of the Population and Community Development Association, one of Thailand's largest private, non-profit development organizations. He was appointed Ambassador for UNAIDS in 1999 and has received numerous awards including the United Nations Population Award in 1997 and the United Nations Gold Peace Medal in 1981.
(www.thaigov.go.th)
(www.sli.unimelb.edu.au/pda/)

Ryan White
American Ryan White became an unwitting international symbol of HIV/AIDS. White was born in 1971 with hemophilia and became infected with HIV in 1984 after receiving contaminated blood during a transfusion. He was shunned by his community but embraced by celebrities such as Elton John. White died in 1990 and soon after then-President George Bush enacted landmark legislation named the Ryan White Comprehensive AIDS Resource Emergency Act which provides care, treatment and services to people with HIV/AIDS in the United States.
(www.careactdatasupport.hrsa.gov/)

Phill Wilson
Wilson is founder and the Executive Director of the Black AIDS Institute, based in Los Angeles, California. It is the only black HIV/AIDS think tank in the United States. Wilson has said the goal of the Institute is to "reduce the HIV health disparities between people of African descent and other racial ethnic groups by engaging black folks in efforts to combat HIV/AIDS." The organization's motto is, "Our people, Our problem, Our solution." Wilson also helped create the National Black Lesbian and Gay Leadership Forum and the National Task Force on AIDS Prevention. He has served as the AIDS Coordinator for the City of Los Angeles and the Director of Policy and Planning at AIDS Project Los Angeles.
(www.blackaids.org)

Wan Yanhai
Dr. Wan is China's most prominent AIDS activist. In 1994, he founded AIZHI (AIDS) Action Project, which for some Chinese is the only source of information available about HIV/AIDS. Dr. Wan established the first telephone hotline for HIV/AIDS information and went on to create a widely used website. His activism led to his dismissal from China's Health Ministry. In 2002, he was detained for several weeks by the government. In 2005, Dr. Wan organized a landmark conference between Shanghai University Law School and Human Rights Watch, an international watchdog organization, to discus how to tackle the growing threat of HIV/AIDS in China.
(www.aizhi.org)

INDIA CONTACTS

Dr SY Quraishi
Special Secretary and Project director
National AIDS Control Organisation'
Ministry of Health and Family Welfare
9th Floor, Chandralok Building,
36, Janpath,
New Delhi 110 001
Tel: 011 2332 5331
Fax: 011 2335 1700
E-mail: ssdg@nacoindia.org

Mr. Cecilio Adorna
Representative
UNICEF
UNICEF House
73, Lodi Estate
Tel: 24690401
Fax: 24627521/24691407
E-mail: cadorna@unicef.org
ebarr@unicef.org

Dr Denis Broun
Country Coordinator
UNAIDS
c/o 55 Lodi Estate
New Delhi – 110003
Tel: 24649892
Fax: 24649895
E-mail: bround@unaids.org
delprador@unaids.org
Nalini.fernandes@undp.org

Dr Salim Habayeb
WHO representative to India
WHO
533-35, A Wing, Nirman Bhawan
New Delhi-110001
Tel: 23018955/23017993/23792779
Fax: 23012450
E-mail: habayebsj@whoindia.org
reddyd@whoindia.org
sudhartop@whoindia.org

Ms Chandni Joshi
Regional Programme Director
UNIFEM
233, Jor Bagh
New Delhi -110003
Tel: 24698297/24604351
Fax: 24622136
E-mail: chandni.joshi@undp.org
firoza.mehrotra@undp.org
suneeta.dhar@undp.org

Dr Maxine Olson
UN resident coordinator and UNDP resident representative
UNDP
55 Lodi Estate
New Delhi –110003
Tel: 24628877 extn 330
Fax: 24629666
E-mail: maxine.olson@undp.org
teresa.kaushal@undp.org
surekha.subarwal@undp.org
alka.narang@undp.org

Dr Dora Warren
Director (Centres for Disease Control)
Global AIDS Programme, India
American Embassy
New Delhi -110021
Tel: 24198570
Fax: 24198612
E-mail: dyw3@cdc.gov
Nhn1@cdc.gov

Mr Ashok Alexander
Gates Foundation
A 10 Qutub Institutional Area
Sanskrit Bhawan
Aruna Asaf Ali Road
New Delhi -110067
Tel: 51003100
E-mail: ashoka@India.GatesFoundation.org

Mr. K. K. Abraham
President, INP+
Flat No.6, Kash Towers
93, South West Boag Road,
T.Nagar, Chennai-600 017
Tel: 044-4329580/4329581
Telefax: 044 432 9582
E-mail: inpplus@vsnl.com

Mr Anand Grover
Lawyers Collective
63/2 Masjid Road, First Floor, Jangpura
New Delhi-110014
Tel: 24377101
24377102
E-mail: aidslaw@vsnl.com
aidslaw1@lawyerscollective.org

Programme Management Unit
7/10, Botawalla Building, 2nd Floor
Horniman Circle, Fort,
MUMBAI -400023
Tel: 022 22676213

Ms Anjali Gopalan
Executive Director,
NAZ Foundation Trust (India)
A-86 East of Kailash
New Delhi-110065
Tel: 011 26910499
Fax: 011 51325042
E-mail: nazindia@bol.net.in

Ms P Kousalya
President
Positive Women Network of South India
No 23 Brindavan Street, West Mambalam
Chennai
Tel: 044 2371 1176
E-mail: poswonet@hotmail.com

Dr Sanjay Pujari
Director, HIV Unit,
Ruby Hall Clinic,
40, Sassoon Road,
Pune 411 011
Mobile: 0 98220 58985
E-mail: san1@medscape.com

Dr Ashok K Rau
Freedom Foundation
180 Hennur Cross
Bangalore
Tel: 080 5440134
Fax: 080 5449766
E-mail: freedom@bgl.vsnl.net.in

Dr Suniti Solomon
Director,
YRG Care,
Voluntary Health Services,
Taramani,
Chennai 600 113
Tel: 044 2254 2929
Fax: 044 2254 2939
E-mail: suniti@yrgcare.org

Dr Soumya Swaminathan
Deputy Director,
Tuberculosis Research Centre,
Mayor V Ramanathan Road,
(Spur Tank Road)
Chetpet,
Chennai 600 031
Tel: 044 2836 9500
Fax: 044 2836 2528
E-mail: soumyas@icmr.org.in

Additional copies of this report (#7408) are available on the Kaiser Family Foundation's website at www.kff.org.

The Kaiser Media Fellowships in Health is a program of the Kaiser Family Foundation. The Kaiser Family Foundation is a US non-profit, private operating foundation dedicated to providing information and analysis on health care issues to policymakers, the media, the health care community, and the general public. The Foundation is not associated with Kaiser Permanente or Kaiser Industries.

The Henry J. Kaiser Family Foundation: 2400 Sand Hill Road, Menlo Park, CA 94025 USA Phone: +1.650.854.9400 Fax: +1.650.854.4800
Washington Office: 1330 G Street N.W., Washington, DC 20005 USA Phone: +1.202.347.5270 Fax: +1.202.347.5274
www.kff.org kaisernetwork.org www.globalhealthreporting.org