ENCYCLOPEDIA OF AIDS
A Social, Political, Cultural, and Scientific Record of the HIV Epidemic
EDITED BY RAYMOND A. SMITH

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A CAUTION TO READERS

The *Encyclopedia of AIDS: A Social, Political, Cultural, and Scientific Record of the HIV Epidemic* is designed to provide general information about HIV/AIDS, primarily for the period 1981–1996. It is not intended, and should not be used, as a medical reference by individuals seeking to make personal decisions about HIV prevention, testing, treatment, or other related matters. Nor is the book intended as a definitive guide to HIV-related laws or policies, which vary greatly from jurisdiction to jurisdiction. Readers with personal concerns regarding HIV/AIDS are strongly encouraged to speak to a qualified health care or legal professional.
The greatest challenge in trying to develop a perspective on HIV/AIDS, especially for those of us who worked to investigate the “new” disease in the early days of the epidemic in the United States, is to get far enough away from it to allow objectivity. For all practical purposes, AIDS is still a “new disease” among humankind.

Keeping the perspective of newness is important, especially for those working to develop prevention interventions for a disease that cannot yet be controlled using traditional technological methods: vaccines are not yet available, treatments are limited, and a cure is still a vision for the future.

Our successes have been real but counted in small increments, with measurement difficult and skepticism abundant. The numbers present a formidable obstacle to our confidence in the effectiveness of prevention efforts. The first 100,000 AIDS cases in the United States were reported over a period of eight years, the second 100,000 cases in a period of only 26 months. By 1996, more than half a million AIDS cases were reported, and more than 300,000 people had died.

Although the number of cases reported each year are expected to level off in the United States, the toll of 60,000 to 80,000 annual new cases and more than 50,000 deaths each year represent by far the highest number and rate of cases in any industrialized country. Because millions of additional adolescents and young adults become potentially at risk each year, the challenge of reducing the number of youths infected with HIV (who will develop AIDS years hence) depends upon continued efforts to educate and provide skills and upon continued availability of resources for prevention.

It may provide perspective on the short history of AIDS since it was first reported in 1981 to examine these years more closely. The first five years of the epidemic can be called the era of discovery. Scientific advances were remarkably rapid—the first cases were identified and described, modes of transmission were documented, the etiologic agent was discovered, tests were developed for screening the blood supply, and AZT, the first antiviral agent for HIV, was licensed.

Only 22 months after the first cases were reported, this devastating syndrome was named and the likely cause and modes of transmission were recognized; as a result, recommendations for preventing AIDS from being transmitted through sexual contact, blood transfusions, and injecting drug use were published. The recommendations, based on carefully studied epidemiological patterns, were published in March 1983 when there were only 1,000 reported cases of AIDS in the entire United States and before the virus causing AIDS was isolated.

Discovery of the virus that caused AIDS led to the development of diagnostic tests. The isolation of the virus and licensing of the HIV antibody test in March 1985 were true prevention successes, with procedures to protect the blood supply in place in all U.S. blood banks just two months later. In addition, uses of the antibody tests in population
surveys showed that the virus was much more common than the numbers of reported AIDS cases indicated. The visible AIDS epidemic had often been referred to as only “the tip of the iceberg,” and the new data proved it to be a much more substantial public health threat.

Around 1986, we entered a new era—this was the beginning of what I call the era of growth. At a Public Health Service-wide planning meeting, it was projected that from 1986 through the end of 1991 about 270,000 AIDS cases would be reported. This prediction made people confront the future: AIDS was not going away. Thousands of people would become sick and die, and increasing services would be required to care for them.

These projections were accompanied by expressions of fear and uncertainty from the public as well as from professionals. AIDS was looked upon as “different” from other public health problems, and we were forced to confront the need for a comprehensive and imaginative response to disease prevention. The rapid growth in numbers of HIV-infected persons who were seriously ill was accompanied by fear, uncertainty, and a recognition of the need to do more to prevent infection and treat HIV disease.

During the mid-1980s, the international epidemic of HIV/AIDS was recognized. At the First International Conference on AIDS in Atlanta, Georgia, in 1985, prominent scientists who attended described the extent of AIDS in sub-Saharan Africa. Throughout the decade, HIV/AIDS spread explosively across the continent.

Fed by the rapid scientific discoveries of the early 1980s, optimism about “conquering AIDS” grew as well. There were promises from the scientific community that a vaccine would be developed shortly. The discovery of AZT made us believe that AIDS soon would become a manageable illness, like diabetes. Government AIDS research, prevention, and care budgets expanded, and the number of people working on the problem grew rapidly.

So much was happening between 1986 and 1991. Government agencies began working with nongovernmental organizations as they realized that community involvement would be a necessary component of successful prevention efforts. Governments and community-based organizations collaborated to provide services in the area of prevention and in providing medical care and social services for the increasing numbers of people with HIV-related disease. Sadly, many of the hundreds of thousands of people hidden below the iceberg’s tip became ill and died—those who were infected during the first five years of the epidemic but didn’t know it.

These years were also characterized by growing news media interest. This interest was accelerated by Rock Hudson’s announcement that he had AIDS and his subsequent death, followed by the saga of Ryan White, a teenager with hemophilia who acquired HIV from infected blood products and was banned from his school out of fear and ignorance. His pioneering and well-documented battle with school discrimination and with the illness itself focused the United States on the need to know more about AIDS—and on the need to be more compassionate.

By the 1990s, increases in the number of reported AIDS cases had slowed in the United States, even though AIDS cases worldwide continued to increase rapidly, particularly in Africa, Southeast Asia, and South America. In the United States, however, the horizons were becoming clearer, and many Americans began to accept and expect
AIDS as part of life. For many, this led to complacency or relapse into high-risk behavior, while for others, concerns about AIDS were more strongly inculcated.

In 1992, what I called the era of the “long haul” began. HIV became the leading cause of death among men between the ages of 25 and 44 in the United States, and the fourth leading cause of death among U.S. women in this same age group. Even though AIDS was “leveling off,” 50,000–60,000 young Americans were dying each year of an illness that was, and still is, preventable.

As a result of this “leveling off,” budgets grew smaller, and HIV/AIDS now competes for prevention and research dollars with many other important health issues. At the same time, it has become clear that HIV is a complicated public health problem, one that is intertwined with many other serious medical and societal problems—multidrug-resistant tuberculosis, poverty, drug use, domestic violence and abuse, and the crumbling infrastructure of public health services.

The HIV epidemic is not one, but many epidemics that are changing and evolving. While the earliest cases were nearly all among white homosexual and bisexual men and male injecting drug users, there has been a marked growth in the proportion of cases among women, infants, and minorities. Public health HIV prevention strategies will have to take into account these complexities, just as the basic science strategies must consider the complex pathogenesis of HIV.

Ongoing efforts continue to focus attention on several key points to maximize prevention effectiveness.

First, AIDS is a devastating disease that prematurely robs people of their health and lives.

Second, HIV infection is preventable. Our detailed knowledge about modes of HIV transmission and about biological and behavioral risk factors guides us in prioritizing prevention efforts. Scientific studies of condom effectiveness, preventing transmission from nonsterile injection equipment, and, especially, the discovery that AZT therapy can reduce the rate of perinatal transmission, provide us with powerful prevention tools.

The coming years should see a dramatic decline in pediatric HIV infection in the United States due to effective prevention efforts. Successes in decreasing sexual transmission of HIV among adult gay men in the United States and among heterosexual men and women in Thailand are dramatic examples of how prevention works. Several studies extend and explain the reasons for these and similar successes. School programs that emphasize knowledge and training in communication and other skills are being shown to delay the onset of sexual activity and alter high-risk behaviors among adolescents, the next generation at risk for AIDS.

Over the course of the epidemic, the successes have been gratifying and have given us strength, but they have been and continue to be pitted against the foes of HIV prevention: denial, discrimination, and scarcity. HIV prevention efforts must be strong enough and remain visible enough to warn and protect current and future generations of young men and women. These prevention efforts will be successful only if they are coupled with sustained, visible efforts to prevent discrimination against those who are infected and at risk.

The third and final lesson is that, particularly on a worldwide basis, we have not done enough. The onslaught of HIV infection continues to overwhelm prevention efforts in most developing countries.
HIV prevention cannot be viewed as a one-time intervention; it must be accepted as a continuous, multigenerational effort that extends well into the lifetimes of our children and their children. Thinking long-term and remaining committed are the key characteristics needed in both science and prevention in order to maximize the chances of conquering HIV.

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Lessons from the Global HIV/AIDS Epidemic

Peter Piot, M.D., Ph.D.

The global HIV/AIDS epidemic has taught, or retaught, us many important lessons. It has confirmed the importance of socioeconomic and cultural factors in health. It has shown that when human rights are not protected, people are more vulnerable to disease. And it has reminded us that, although infectious diseases once seemed to be on the wane, a new worldwide epidemic can break out at any moment.

Perhaps the most sobering lesson of the past 15-plus years is that the HIV/AIDS epidemic has not turned out to be a disease outbreak that science can quickly bring under control. Both a vaccine and a cure remain elusive. There are no quick fixes, technological or otherwise, to prevent new infections or eliminate the lingering societal impact of millions of AIDS deaths among individuals in their peak productive and reproductive years.

The most hopeful lesson is that, even though our approaches are imperfect, we are not powerless against the epidemic. Communities in the developing world, and even some industrialized nations as a whole, have managed to stabilize or reduce the rate of new HIV infections, provide care and support for those infected or affected, and combat fear and rejection of people living with HIV and AIDS.

Scientific advances hold out even greater hope for the future. Combined antiviral drugs promise longer and higher quality survival for HIV-infected people. Antiviral treatment for women and their newborn babies has been shown to reduce mother-to-child transmission. Progress is being made in developing vaginal creams and other “barriers” to HIV that women can apply. Insights for both vaccine and drug development are emerging from the study of individuals who appear resistant to HIV infection or who remain remarkably disease-free years after becoming infected. Yet with more than 20 million HIV-infected people alive and facing an unpredictable and generally fatal course, and with more than 7,500 new HIV infections occurring each day, it is premature to claim that we have turned the corner.

Difficulties and obstacles abound. Denial has diminished since the early years of the epidemic but continues to block political commitment and individual action. Those most affected—the people who are infected with or at risk of HIV—still often have no voice in designing and planning action and services. Harm reduction measures, such as access to condoms or sterile needles, continue to be controversial despite their effective track record. In countries with resource-starved or poorly managed health services, people with HIV/AIDS suffer for lack of the simple drugs that could ease their pain, itching, or nausea, not to mention a total lack of access to antiviral drugs.

Prevention is still divorced from care and support, and measures are geared to outbreak control instead of lifetime HIV risk management. Moreover, in the context of
people’s lives, many key prevention messages are irrelevant. Where homosexuality is criminalized or heavily stigmatized, gay men may have no realistic way of obtaining condoms to prevent HIV infection or health care once they have HIV or AIDS. To take another example, mutual sexual fidelity may protect from HIV, but it is something over which many married women have no control. The lack of realistic options for self-protection—whether because of poverty, power imbalances, or denial of human rights—results in appalling vulnerability for billions of men, women, and children.

Only an expanded response to the epidemic gives us a chance of grappling with these problems. The response needs to be of greater duration, in keeping with the permanent nature of the AIDS challenge; of greater quality, bearing in mind the ineffectiveness of technically inappropriate and poorly managed action; and of greater scope, encompassing but reaching far beyond the health sector.

The fact that HIV and its repercussions will be with us for generations implies the need for a sustainable response, one that encourages openness about the epidemic among individuals and communities and that builds up their coping capacity. Among other things, coping means lifelong acceptance and inclusion of people with HIV/AIDS in the household or community and the adjustment of personal behavior to the lifelong risk of HIV infection.

But while the action required must always be viewed through the lens of human needs, it cannot be limited to the personal or individual level. We must act on the broad structural context of prevention, care, and impact alleviation.

At one end of the spectrum, we need to tackle the underlying socioeconomic and structural factors that make people vulnerable to HIV/AIDS and by giving them few realistic options for self-protection. Empowerment for action is one obvious remedy. To return to the example of women, vulnerability could be lessened through increased education, access to credit, and equitable rights in the event of divorce. Clearly, such action could simultaneously diminish women’s vulnerability to other ills with similar socioeconomic roots, including violence and unwanted pregnancy.

At the other end of the spectrum, we might want to reduce risk options, for example by raising taxes on risk-related products such as alcohol or through “seat-belt” constraints such as the Thai policy of obligatory condom use in brothels, which eliminates the client’s risk option of unprotected sex and at the same time “empowers” the sex worker to insist on condom use.

We must be wary of venturing too far into structural or coercive risk reduction, however, and not only for human rights reasons. Government coercion is rarely neutral, because it tends to constrain the powerless rather than the powerful. For example, although sexual HIV transmission is obviously a two-way risk, far more coercion is typically applied to sex workers than to sex work clients, increasing the power imbalance instead of leveling the playing field.

Like prevention, the provision of care and support for people affected by HIV and the alleviation of the epidemic’s impact necessarily involve a wide range of actors, processes, and sectors. Not all the links are obvious, however. For example, in high-prevalence countries, the interface between AIDS and schools is not limited to introducing lifestyle skills or sex education into the curriculum but involves training extra principals and teachers to replace those dying of AIDS. The implications of AIDS for agriculture are not simply that children are taken out of school to weed fields that their sick parents cannot
tend but also the threat that parents will not live long enough to pass on their precious knowledge of soil conservation and crop rotation. In sum, an expanded response also means weaving AIDS issues and implications into social and economic development.

Realistically, what can an expanded response achieve? A smaller epidemic involving a more tolerable level of suffering. Expanded response will not, however, stop the epidemic. Short of universal population coverage with a highly effective HIV vaccine, we cannot expect all transmission to cease.

In terms of future challenges, what we do about AIDS depends on how we look on the epidemic—as a mere disease, a failure to respect religious codes, an outcome of differentials in sexual behavior and sexual decision-making between men and women, a human rights issue, or another tragic correlate of poverty and deprivation, to name but a few of the paradigms that have evolved since the start of the epidemic. It is illusory to think that these competing paradigms can ever be reduced to a single world view. The overlaps, such as between the human rights and the poverty paradigms, and even the frank contradictions, for example between biomedical and religious models, mirror the complexities of real life. Sometimes we are at a loss even to understand why a particular community has been successful in lowering transmission. Humility will help us avoid the straight jacket of AIDS orthodoxy and narrow-minded political correctness.

Nevertheless, there do appear to be some universally applicable principles. One is the need for the simultaneous use of multiple approaches that can work together. Another principle is never to lose sight of the epidemic’s disproportionate focus on individuals and communities already facing other health, social, and economic challenges, such as women, young people, sexual and ethnic minorities, refugees, drug users, and economically disadvantaged populations. It is no coincidence that more than 90 percent of all new infections now occur in the developing world. An expanded response from the industrialized countries is essential today but also tomorrow, as more effective drugs, HIV barriers, and hopefully vaccines are developed and access by people in the developing countries becomes an ever-greater moral imperative.

As people increasingly demand to know their HIV infection status, a further challenge will be to provide them with voluntary counseling and testing. This can open the way to new ways of coping with the epidemic. Counseling and HIV testing, followed by mutual agreement and trust by the partners to protect each other from HIV, may become the standard prelude to a long-term relationship, with or without procreation. It might be particularly useful in communities where any prospective partner has a high likelihood of being infected, such as parts of Africa where 20 percent of 20-year-olds have HIV. A related challenge will be to offer more effectively tailored support for the real needs of people diagnosed with HIV infection, not only their right to nondiscrimination in areas such as housing, employment, and travel, but their right to care and their needs for intimacy during the decade or more that they can expect to live with the virus.

In conclusion, the worldwide HIV/AIDS epidemic has become a permanent challenge to human integrity and solidarity. Given the scale of suffering, given the proven effectiveness of several approaches, and given the prospect of furthering other human goals through the fight against AIDS, an expanded response makes ethical and practical sense. Instead of letting AIDS turn back the clock, let us use our response to the epidemic to turn humanity’s clock ahead.
Peter Piot, a Belgian physician and microbiologist, is executive director of the Joint United Nations Programme on HIV/AIDS (UNAIDS), headquartered in Geneva, Switzerland. A co-discoverer of Ebola virus in 1976, he later launched and expanded a series of collaborative projects on AIDS in Africa. This essay was written in collaboration with Suzanne Cherney of UNAIDS.
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EDITOR’S NOTE AND GUIDE TO USAGE

First and foremost, acquired immunodeficiency syndrome (AIDS) has been a personal tragedy for millions of people throughout the world—both those who have suffered with and died from AIDS as well as those who struggle with it still. It is these men and women who have borne the brunt of the epidemic, often with inspiring dignity and courage.

In addition to being a personal tragedy, AIDS has proven to be a social challenge, a cultural catharsis, a political quagmire, and a scientific puzzle. Perhaps more than any other threat to the public health in modern times, the AIDS epidemic has entangled not only individuals but also families and friends, cultures and communities, cities and nations throughout the world. It has cut across race and ethnicity, class and education, age and religion, gender and sexual orientation, challenging the compassion and ingenuity of humankind at every turn.

Because of the extraordinary sweep of the epidemic, tens of thousands of specialized works have been published about the social, political, cultural, and scientific dimensions of AIDS and its causative agent, the human immunodeficiency virus (HIV). Yet, to date, no single volume has ever sought to systematically organize, synthesize, and contextualize this enormous body of information for a general readership. The Encyclopedia of AIDS: A Social, Political, Cultural, and Scientific Record of the HIV Epidemic is the first reference work to undertake such a task by covering all major aspects of the global HIV/AIDS crisis.

Structure of the Encyclopedia of AIDS

The enormity and complexity of the ongoing HIV/AIDS epidemic is such that this work might have been 10 volumes rather than one and included 2,500 entries rather than the roughly 250 it contains. Inevitably, however, even the most extensive and exhaustive reference work would be outdated to some degree as soon as it was published, given the rapidly changing state of scientific knowledge as well as new developments in the social, political, and cultural dimensions of the epidemic.

Thus, the construction of the Encyclopedia of AIDS posed several challenges: to cover a topic of extraordinary magnitude within the bounds of a ready-reference, single-volume format; to render extremely complex subjects accessible to a wide range of readers while avoiding oversimplification; and to produce a volume that would continue to be of value for several years after its initial publication. To meet these challenges, the Encyclopedia of AIDS approaches the first 15 years of the AIDS epidemic as a historical phenomenon unto itself, the broad profiles of which can be captured even if all its details cannot be spelled out in such a limited space. Recognizing that cutting-edge information about
HIV/AIDS will forever be a moving target better left to periodicals and on-line resources, the Encyclopedia focuses instead on providing a record of the first 15 years of the epidemic.

In keeping with this approach, the Encyclopedia takes as its starting point the summer of 1981, when the first cases of unexplained immune deficiency began to be identified among a handful of gay men in the United States. The Encyclopedia continues its coverage through the summer of 1996, when the class of potent antiviral medications called protease inhibitors entered public consciousness, raising the first real hopes that HIV might someday be defeated. While the AIDS epidemic was influenced by many events prior to the summer of 1981 and the summer of 1996 by no means signalled the epidemic’s end, these two events represent major historical markers. Of course, many precedents from prior to the summer of 1981 are also discussed, some stretching back decades or centuries. Likewise, a significant number of entries cover developments which occurred in 1997. In addition, dozens of historical photos and illustrations are included, most drawn from the period 1981–1996.

Using the Encyclopedia of AIDS

As a general reference work, the Encyclopedia of AIDS is intended to be a first step for general readers seeking information about HIV/AIDS as well as for specialists wishing to learn more about topics outside their areas of expertise. For those seeking information beyond what is offered in any individual article, each entry includes a list of Related Entries within the Encyclopedia, Key Words for use in on-line searches, and suggestions for English-language Further Reading. At the front of the Encyclopedia, a Resource Guide provides lists of periodicals, Internet sites, organizations, and other sources of information for readers who wish to update the information contained in the entries. Additional materials include an alphabetical list of all entries and a List of Commonly Used Terms and Abbreviations.

The contents of the Encyclopedia of AIDS can be organized into eight broad domains: Basic Science and Epidemiology; Transmission and Prevention; Pathology and Treatment; Impacted Populations; Government and Activism; Policy and Law; Culture and Society; and the Global Epidemic. The Overview provides a synopsis of the key facts in each domain, an explanation of the manner in which that domain is covered in the Encyclopedia, and a list of all relevant entries.

The 250 entries in the main body of the Encyclopedia are listed alphabetically. The headings of entries generally were chosen to reflect the word or words that general readers would be most likely to look up and also to afford as much symmetry as possible with related entries. Nonetheless, many subjects are not covered under their own headings but rather as part of larger entries; thus, readers are strongly encouraged to make maximum use of the Index at the back of the Encyclopedia.
Contributors

The 250 entries have been written by 181 contributors from more than a dozen countries on five continents. Collectively, the contributors represent many of the finest research institutes, colleges and universities, government agencies, community-based organizations, activist groups, and other institutions involved with combating the HIV/AIDS epidemic. Information on all contributors is offered in the Notes on Advisers and Contributors. Each entry also includes the name(s) of its author(s). Co-authors have their names linked by the word “and.” A secondary author who contributed a significant but limited portion of a larger entry is noted as having written the entry “with” the primary author(s). While most co-authorships were initiated by the contributors during the writing stage, some were initiated by the editors when the most efficient use of limited space required that closely related entries be merged. Thus, co-authorship of an entry does not necessarily imply a working relationship or a mutual endorsement between the co-authors.

In order for the Encyclopedia of AIDS to emerge as a single, coherent entity that would be of maximum use to readers, all contributors were asked to write their entries from the perspective of the “mainstream consensus” that has emerged over the last 15 years regarding the causes and nature of the AIDS epidemic. While it is difficult to quantify precisely this mainstream consensus, its cornerstone is that HIV is a naturally occurring (rather than human-made) virus and that HIV is the principal cause of AIDS (although certain co-factors may exist). Well into the second decade of the epidemic, some scientists and others continue to question the extraordinary volume of evidence that supports this mainstream consensus. While such dissention can play a useful role in the construction of scientific knowledge, it was nonetheless felt that as a general reference work, this volume should reflect the facts about HIV/AIDS as most commonly agreed upon throughout the world. Contributors were asked to note when certain facts are generally considered to be speculative or conjectural within the mainstream consensus.

Similarly, authors were also asked to avoid writing entries that indulge in polemics or advocate one point of view to the exclusion of all others. Although contributors were asked to approach their entries from within the bounds of scholarly objectivity, most entries nonetheless do, to some degree, reflect the disciplinary, theoretical, and ideological perspectives of their authors. It should also be noted that the source materials used to prepare the entries vary from entry to entry. Rather than require contributors to adhere to a single source of information, they were left to rely upon their own experience and professional expertise to determine the most reliable and appropriate source of information for their specific articles. Consequently, there may be small discrepancies in certain points of information in different entries.
Editorial Policy

In the face of severe space constraints, a number of difficult decisions about editorial policy had to be made about the way in which individuals, institutions, and countries would be covered. Thousands of people have played important roles in various aspects of the AIDS epidemic, enough so that an entire volume could easily be consumed with biographical entries alone. Yet there are no clear rules to follow in determining whom to include in separate entries and whom to exclude. Therefore, it reluctantly was decided that there would be no biographical entries, but that the names of prominent people would be allowed to emerge within the context of other entries. In addition, several articles are devoted to categories of individuals, such as “Artists and Entertainers” and “Politicians and Policymakers.” Much the same is the case for organizations and institutions, which do not as a rule have specific entries assigned to them but rather are discussed in the context of other entries or in entries devoted to categories such as “Professional Organizations” and “Service and Advocacy Organizations.” Similarly, most countries are profiled within the context of their world regions rather than on a nation-by-nation basis. (The Overview section on “The Global Epidemic” includes a list of the world regions and the countries listed in each.)

Ultimately, the contents of the Encyclopedia were shaped not only by deliberate design and by the limitations of space, but also by idiosyncrasies of the editorial process. No claim is made that the organization or weighting of materials in this volume is the only, or even the single best, possible way in which the vast store of information about HIV/AIDS could be organized. Indeed, it will always be possible to argue that one or another topic should have been covered in greater depth or from a different perspective, or to ask why one topic was included and another not included. On a topic as important and politically charged as HIV/AIDS, fair-minded people can and do disagree on a multitude of issues. Nonetheless, we believe that all of the most crucial dimensions of the HIV/AIDS epidemic between 1981 and 1996 have been touched upon.

Readers are encouraged to send reaction to this volume and suggestions for possible future editions to:

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RAYMOND A. SMITH
New York, March 1998
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ALPHABETICAL LIST OF ENTRIES

Abstinence
ACT UP
Adolescents
Africa, East-Central
Africa, Southern
Africa, West
African Americans
AIDS, Case Definition of
AIDS, Pathogenesis of
AIDS-Related Complex (ARC)
Anal Intercourse
Animals
Antibodies
Antioxidants
Antiviral Drugs
Artists and Entertainers
Arts Community
Asia, East
Asia, South
Asia, Southeast
Asian and Pacific Islander Americans
Australia and New Zealand
Babies
Bacterial Infections
Bathhouse Closure
B Cells
Bereavement
Bisexuality
Bisexuals
Blood
Blood Abnormalities
Blood Transfusions
Buddhism
Canada
Caregiving
Caribbean Region
Catholic Church
Cervical Cancer
Chemotherapy
Children
Child Sexual Abuse
Chinese Medicine
Christian Denominations, Smaller
Clinical Trials
College and University Students
Complementary and Alternative Medicine
Condoms
Confidentiality
Congress, U.S.
Conspiracy Theories
Contact Tracing and Partner Notification
Correctional System
Counseling
Couples
Court Cases
Cure
Cytomegalovirus (CMV)
Dance and Performance Art
Death and Dying
Dementia
Demonstrations and Direct Actions
Dental Dams
Dentistry
Developmental Disabilities, People with
Disabilities, People with
Disclosure
Discrimination
Drug Outreach Projects
Drug Resistance
Drug Use
Economics
Educational Policy
Emergency Workers
Enteric Diseases
Epidemics, Historical
Ethics, Personal
Ethics, Public
Europe, Eastern
Europe, Northern
Europe, Southern
Families
Family Policy
Feminism
Film
Forecasting
Fraud and Quackery
Fungal Infections
Gay and Lesbian Organizations
Gay Men
Gay Rights
Gender Roles
Gene Therapy
Geography
GRID (Gay-Related Immune Deficiency)
Harm Reduction
Health Care Reform
Health Care Workers
Hemophilia, People with
Hepatitis
Herpes
Heterosexual Men
High School Students
Hinduism
HIV, Description of
HIV, Origins of
HIV Infection, Resistance to
Homeless Populations
Homophobia
Housing
HTLV
Human Papillomaviruses
Human Rights
Immigration and Travel Restrictions
Immune-Based Therapies
Immune System
Informed Consent
Injecting Drug Use
Injecting Drug Use, Subculture of
Injecting Drug Users
Insurance
International Organizations
Internet
Interventions
Islam
Journalism, Print
Journalism, Television
Judaism
Kaposi’s Sarcoma (KS)
Kidney Complications
Kissing
Latinos
Legislation, U.S.
Lesbians
Literature
Long-Term Survivors and Non-Progressors
Lubricants
Lymphadenopathy
Lymphoid Interstitial Pneumonia (LIP)
Lymphoma
Malnutrition
Manual-Digital Sex
Marches and Parades
Masturbation
Maternal Transmission
Media Activism
Mental Health
Mental Illnesses, People with
Mexico and Central America
Middle East and North Africa
Migration
Military
Ministries
Monocytes and Macrophages
Monogamy
Mouth
Music
Mycobacterium avium Complex
National AIDS Programs
Native Americans
Natural Killer Cells
Needle-Exchange Programs
Nervous System, Central
Nervous System, Peripheral
Nursing
Older Adults
Oral Sex—Anilingus
Oral Sex—Cunnilingus
Oral Sex—Fellatio
Pain
Periodicals
Pneumocystis carinii Pneumonia (PCP)
Political Parties, U.S.
Politicians and Policy Makers, U.S.
Pornography
Poverty
Presidency, U.S.
Professional Organizations
Progressive Multifocal Leukoencephalopathy (PML)
Prophylaxis
Prostitution
Protestant Churches
Public Assistance
Public Opinion
Public Sex Environments
Quarantine
Queer Theory
Racism
Radio
Religious Faith and Spirituality
Retroviruses
Russia and the Former Soviet Union
Sadomasochism
Safer Sex
Safer-Sex Education
Saliva
Semen
Seroconversion
Seroprevalence
Service and Advocacy Organizations
Sexism
Sexual Assault
Sexually Transmitted Diseases
Sex Work
Side Effects and Adverse Reactions
Skin Diseases
Social Construction
Social Work
South America
Sports and Sports Figures
State and Local Government, U.S.
Stigma
Suburban and Rural Populations
Suicide and Euthanasia
Support Groups
Surveillance
Symbols
Tattooing, Piercing, and Scarification
T Cells
Television Programming
Testing
Testing Debates
Theater
Toxoplasmosis
Transgendered People
Transmission, Misconceptions About
Transplantation
Tuberculosis
Underground Treatments
United Kingdom and Republic of Ireland
United States—Middle Atlantic Region
United States—The Midwest
United States—Mountain Region
United States—New England
United States—The South
United States—The Southwest
United States—Western Pacific Region
United States Government Agencies
Universal Precautions
Vaccines
Vaginal and Cervical Secretions
Vaginal Intercourse
Visual Arts
Vitamins and Minerals
Wasting Syndrome
Water and Food Safety
Women
Workplace Issues
World AIDS Day
Writers
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RESOURCES GUIDE

This Resource Guide is designed to help readers who wish to update information and seek out further information about HIV/AIDS issues beyond what is covered in the Encyclopedia of AIDS. Given that there are frequent developments in the social, political, cultural, and especially the scientific dimensions of the epidemic, readers are encouraged to seek out the most up-to-date information available about HIV/AIDS. The resources listed below were chosen specifically to provide readers with a broad range of information sources. Inclusion in this Resource Guide, however, does not imply an endorsement by the Encyclopedia of AIDS.

Included in this Resource Guide are:

- U.S. Publications on HIV/AIDS
- U.S. Federal and State Government Documents
- International English-Language Periodicals on HIV/AIDS
- Major North American HIV/AIDS Information Centers, Libraries, and Subject Collections
- Major U.S. HIV/AIDS Organizations
- Major HIV/AIDS Contacts in the United Kingdom and Canada
- Major International HIV/AIDS Organizations
- Internet Resources

U.S. Publications on HIV/AIDS

Acquired Immune Deficiency Syndrome Newsletter
ISSN 1041–4487
Biweekly
AIDS Newsletter
1680 N. Vine St., Ste. 316
Los Angeles, CA 90028

AIDS Care
ISSN 0954–0121
Carfax Publishing Co.
875–881 Massachusetts Ave.
Cambridge, MA 02139
AIDS Patient Care  
ISSN 0893–5068  
Bimonthly  
Mary Ann Liebert, Inc.  
2 Madison Ave.  
Larchmont, NY 10538

AIDS Policy and Law  
ISSN 0887–1493  
Biweekly  
LRP Publications  
Box 980  
747 Dresher Rd.  
Horsham, PA 19044–0980

AIDS & Public Policy  
ISSN 0887–3852  
Quarterly  
University Publishing Group, Inc.  
107 E. Church St.  
Frederick, MD 21701

AIDS Research and Human Retroviruses  
ISSN 0889–2229  
Quarterly  
Mary Ann Liebert, Inc.  
1651 Third Ave.  
New York, NY 10128

AIDS Therapies  
Monthly  
Charles W.Henderson  
Box 5528  
Atlanta, GA 31107–0528

AIDS Treatment News  
Semimonthly  
John S.James  
P.O. Box 411256  
San Francisco, CA 94141

AIDS Weekly  
ISSN 1069–1456  
Weekly  
Charles W.Henderson
Box 5528
Atlanta, GA 31106–0528

Archives of STD-HIV Research
ISSN 1071–0906
Quarterly
Reproductive Health Center
78 Surfsong Rd.
Siawah Island, SC 29455

Art & Understanding
ISSN 1074–0872
Art & Understanding, Inc.
25 Monroe St., Ste. 205
Albany, NY 12210

Being Alive Newsletter
Monthly
Being Alive, People with HIV-AIDS Action Coalition
3626 Sunset Blvd.
Los Angeles, CA 90026

BETA (Bulletin of Experimental Treatments for AIDS)
San Francisco AIDS Foundation
Box 6182
San Francisco, CA 94101

Body Positive
ISSN 1048–4396
Monthly
Body Positive, New York
19 Fulton St., Ste. 308B
New York, NY 1003 8

FOCUS (San Francisco)
ISSN 1047–0719
Irregular
Aids Health Project

University of California, San Francisco
Box 0884
San Francisco, CA 94143–0884
GMHC Treatment Issues  
ISSN 1077–1824  
Monthly  
Gay Men’s Health Crisis, Inc.  
Department of Medical Information  
129 W. 20th St.  
New York, NY 10011

HIV/AIDS  
Quarterly  
HIV/AIDS Epidemiology Unit, Seattle-King County Department of Health  
HIV/AIDS Epidemiology Unit  
Department of Social and Health Services  
Seattle, WA

In Development, AIDS Medicine, Drugs and Vaccines  
Pharmaceutical Manufacturers Association  
Washington, D.C.

Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology  
ISSN 1077–9450  
Irregular  
Lippincott-Raven Publishers  
227 E. Washington Sq.  
Philadelphia, PA 19106

Notes From the Underground  
PWA Health Group  
31 W. 26th St., 4th Fl.  
New York, NY 10010  
P.I. Perspective (Project Inform)  
1965 Market St., Ste. 220  
San Francisco, CA 94103

POZ  
ISSN 1075–5705  
Bimonthly  
Strubco Media Group, Inc.  
Old Chelsea Station  
P.O. Box 1274  
New York, NY 10113–1279
AIDS Bibliography (National Library of Medicine)

Published on a quarterly basis, the AIDS Bibliography contains citations to preclinical, clinical, epidemiological, diagnostic, and prevention areas added to the National Library of Medicine’s MEDLINE and CATLINE databases. Online access to the National Library of Medicine’s AIDSDRUGS/AIDSTRIALS and AIDSLINE databases is also available through the agency’s MEDLARS system.

These databases provide up-to-the-minute information on new drugs and corresponding drug trials and citations for new research published in the field.

Monthly Catalog of United States Government Publications (Government Printing Office)

This catalog lists all government publications printed, processed, and issued by the U.S. Government Printing Office along with other agencies. Each monthly issue of the Monthly Catalog contains a subject, author, title, and title keyword index, which is cumulated annually. All citations contain succinct bibliographic information about the document.

Monthly Checklist of State Publications (Library of Congress)

The Monthly Checklist is a listing of all state documents issued during the last five years and received by the Library of Congress. A cumulative annual subject index facilitates retrieving pertinent citations. Each entry includes relevant bibliographic information and lists the state agency responsible for publishing the material(s).

Subject Bibliography (SB 315), AIDS (Acquired Immune Deficiency Syndrome) (Library of Congress)

Subject Bibliography (SB 315) provides the public with a current list of publications for sale by the Superintendent of Documents on the issue of AIDS. The list is updated on an irregular basis, and the material posted is not cumulated.
Abingdon, OX OX14 3UE
tel. 01235–555335

AIDS Directory
NAM Publications
52 Eurolink Centre
49 Effra Rd.
London SW2 1BZ
England
tel. 0171–737–1846

AIDS Letter
Royal Society of Medicine Press, Ltd.
1 Wimpole St.
London W1M 8AE
England
tel. 0171–290–2900

AIDS Newsletter
CAB International
Wallingford, OX OX10 8DE
England
tel. 800–528–4841

AIDS Reference Manual
NAM Publications
52 Eurolink Centre
49 Effra Rd.
London SW2 1BZ
England
tel. 0171–737–1846

AIDS Update
Ministry of Health, Centre for Disease
Control
828 W. 10th Ave.
Vancouver, BC V5Z 1L8
Canada

Canadian AIDS News/SID A: Realites
Canadian Public Health Association
1565 Carling Ave., Ste. 400
Ottawa, ON K1Z 8R1
Canada
tel. 613–725–3679
European AIDS Directory
NAM Publications
52 Eurolink Centre
49 Effra Rd.
London SW2 1BZ
England
tel. 0171–737–1846

European Centre for the Epidemiological Monitoring of AIDS
Hopital National de Saint-Maurice
14 rue du Vald’Osne
94110 Saint-Maurice, France
tel. 43–96–65–45

Global AIDSNews
World Health Organization, Global Programme on AIDS
CH-1211
Geneva 27, Switzerland
tel. 791–4650

HIV/AIDS Legal Link
AFAO Secretariat
P.O. Box H274
Australia Square
Sydney, NSW 2000
Australia
tel. 61–2–231–2111

HIV & AIDS Treatment Directory
NAM Publications
52 Eurolink Centre
49 Effra Rd.
London SW2 1BZ
England
tel. 0171–737–1846

HIV Herald
AFAO Secretariat
P.O. Box H274
Australia Square
Sydney, NSW 2000
Australia
tel. 61–2–231–2111

International Journal of STD & AIDS
Royal Society of Medicine Press, Ltd.
1 Wimpole St.
London W1M 8AE
England
tel. 0171–290–2900

International Update
NAM Publications
52 Eurolink Centre
49 Effra Rd.
London SW2 1BZ
England
tel. 0171–737–1846

National AIDS Bulletin
AFAO Secretariat
P.O. Box H274

Australia Square
Sydney, NSW 2000
Australia
tel. 61–2–231–2111

PHLS HIV Bulletin
Public Health Laboratory Service
61 Colindale Ave.
London NW9 5HT
England
tel. 0181–200–4400

PHLS Library Bulletin
Public Health Laboratory Service
61 Colindale Ave.
London NW9 5HT
England
tel. 0181–200–4400

WHO AIDS Series
World Health Organization
Distribution and Sales
1211 Geneva 27,
Major North American HIV/AIDS Information Centers, Libraries, and Subject Collections

AID Atlanta
1438 W. Peachtree St.
Atlanta, GA 30309

AIDS Information Network
1211 Chestnut St., 7th Fl.
Philadelphia, PA 191
tel. (215) 575–1110

Gay Men’s Health Crisis
129 W. 20th St., 2nd Fl.
New York, NY 10011
tel. (212) 807–6655

Healing Alternatives Foundation Library
1748 Market St., Ste. 204
San Francisco, CA 94102

HIV Fight Back Library
3626 Sunset Blvd.
Los Angeles, CA 90026

HIV Resource Library
AIDS Action Committee
131 Clarendon St.
Boston, MA 02116

National AIDS Clearing House
400–1565 Carling Ave.
Ottawa, Ontario
Canada K1Z8R1
tel. (613) 725–3434

National AIDS Clearinghouse Online
Centers for Disease Control and Prevention
5600 Fishers Lane
Parkway Bldg. #1834
National Library of Medicine
8600 Rockville Pike
Bethesda, MD 20894
tel. (800) 638–8480

Project Inform
1965 Market St., Ste. 220
San Francisco, CA 94103
tel. (800) 822–7422

Ron Shipton HIV Information Center
715 N. San Vincente
West Hollywood, CA 90069

Test Positive Aware Network
1258 W. Belmont Ave.
Chicago, IL 60657
tel. (773) 404–8726

University of Michigan Library
Special Collections Library
Lon C. Nungesser Papers
Ann Arbor, MI 48109
tel. (313) 764–9377

University of Wisconsin, Madison
William S. Middleton Health Sciences Library
Historical Collection
1305 Linden Dr.
Madison, WI 53706
tel. (608) 262–2371

Major U.S. HIV/AIDS Organizations

ActionAIDS
1216 Arch St.
Philadelphia, PA 19107
tel. (215) 981–0088
AIDS Action Committee
131 Claredon St.
Boston, MA 02116
tel. (617) 437–6200

AIDS Community Resource Network
P.O. Box 2057
Lebanon, NH 03766
tel. (603) 448–2222

AIDS Foundation San Diego
140 Arbor Dr.
San Diego, CA 92103
tel. (619) 686–5050

AIDS Project Los Angeles
1313 N. Vine St.
Los Angeles, CA 90028
tel. (213) 993–1600

AIDS Project New Haven
P.O. Box 636
New Haven, CT 06503
tel. (203) 624–0947

AIDS Resource Center of Wisconsin
820 N. Plankinton
P.O. Box 92487
Milwaukee, WI 53202
tel. (414) 273–1991

AIDS Services of Austin
P.O. Box 4874
Austin, TX 78765
tel. (512) 451–2273

AIDS Services of Dallas
P.O. Box 4338
Dallas, TX 75208
tel. (214) 273–1991

AIDS Survival Project
828 W. Peachtree St., Ste. 206
Atlanta, GA 30308
tel. (404) 874–7926
AIDS Task Force of Greater Cleveland
2728 Euclid Ave., Ste. 400
Cleveland, OH 44115
tel. (216) 621–0766

Alaskan AIDS Assistance Association
1057 W.Faired #102
Anchorage, AK 99503
tel. (907) 263–2052

Arizona AIDS Project
4460 N.Central Ave.
Phoenix, AZ 85012
tel. (602) 265–3300

Body Positive
19 Fulton St., Ste. 308B
New York, NY 1003 8
tel. (212) 566–7333

Boulder County AIDS Project
2118 14th St.
Boulder, CO 80302
tel. (303) 444–6121

Cascade AIDS Project
620 S.W.Fifth, Ste. 300
Portland, OR 97204
tel. (503) 223–5907

Columbus AIDS Task Force
1500 W.Third Ave., Ste. 329
Columbus, OH 43212
tel. (614) 488–2437

Food & Friends
58 L St., SE
Washington, D.C. 20003
tel. (202) 863–1840

God’s Love We Deliver
166 Avenue of the Americas
New York, NY 10013
tel. (212) 294–8100
Health Crisis Network
5050 Biscayne Blvd.
Miami, FL 33137
tel. (305) 751–7775

Housing Works
594 Broadway, Ste. 700
New York, NY 10012
tel. (212) 966–0466

Iowa Center for AIDS Resources/Education
P.O. Box 2989
Iowa City, IA 52244
tel. (319) 338–2135

Midwest AIDS Prevention Project
702 Livernois
Ferndale, MI 48220
tel. (810) 545–1435

Minnesota AIDS Project
1400 Park Ave.
Minneapolis, MN 55404
tel. (612) 373–2437

Nebraska AIDS Project
3610 Dodge St., Ste. 110-W
Omaha, NE 68131
tel. (402) 342–6367

New Mexico AIDS Services, Inc.
4200 Silver Ave., SE #D
Albuquerque, NM 87108
tel. (505) 266–0911

NO/AIDS Task Force
1407 Decatur St.
New Orleans, LA 70116
tel. (504) 945–4000

Northwest AIDS Foundation
127 Broadway East #200
Seattle, WA 98102
tel. (206) 329–6923
Open Hand Chicago
909 W. Belmont Ave., Ste. 100
Chicago, IL 60657
tel. (773) 665–1000

Peninsula AIDS Foundation
326 Main St.
Newport News, VA 23601
tel. (804) 591–0971

People With AIDS Coalition-Houston
3400 Montrose Blvd., Ste. 106
Houston, TX 77006
tel. (713) 522–5428

Phoenix Body Positive
4021 N. 30th St.
Phoenix, AZ 85016
tel. (602) 955–4673

Pittsburgh AIDS Task Force
905 West St., 4th Fl.
Pittsburgh, PA 15221
tel. (412) 242–2500

Project Angel Food
7574 Sunset Blvd.
Los Angeles, CA 90046
tel. (213) 845–1800

Project Open Hand
1080R Euclid Ave. N.E.
Atlanta, GA 30307

Project Open Hand
2720 17th St.
San Francisco, CA 94110
tel. (415) 558–0600

San Francisco AIDS Foundation
10 United Nations Plaza
San Francisco, CA 94192
tel. (415) 487–3000

Shanti Project
1546 Market St.
Major HIV/AIDS Contacts in the United Kingdom and in Canada

United Kingdom

National AIDS Helpline
tel. 0800 567123 (24 hours every day)

National AIDS Manual
16a Clapham Common Southside
London SW4 7AB
England
tel. 0171–627–3200
http://www.nam.org.uk/

National AIDS Trust
New City Cloisters
188–196 Old Street
London EC1V 9FR
England
tel. 0171–814–6767
http://www.nat.org.uk/nat

Terrence Higgins Trust
52–54 Grays Inn Road
London WC1X 8JU
England
tel. 0171–831–0330
Helpline 0171–242–1010
http://www.tht.org.uk/

U.K. Coalition of People Living with
HIV/AIDS
250 Kennington Lane
London SE11 5RD
England
tel. 0171–820–2180

Canada

Bureau of HIV/AIDS & STD
Laboratory Centre for Disease Control
Tunney’s Pasture 0202A
Ottawa, Ontario
Canada K1A 1B5

Canadian AIDS Society
400–100 Sparks St.
Ottawa, Ontario
Canada K1P 5B7
tel. 613–230–3580 or 800–884–1058
fax 613–563–4998
e-mail: cdnaids@cyberus.ca

Canadian Public Health Association AIDS Program
400–1565 Carling Ave.
Ottawa, Ontario
Canada K1Z 8R1
tel. 613–725–3769, ex. 131
fax 613–725–9826
e-mail: canews@cpha.ca

National AIDS Clearinghouse
tel. 613–725–3434
fax 613–725–1205
e-mail: aids/sida@cpha

Major International HIV/AIDS Organizations

Global Network of People Living with HIV/AIDS (GNP+)
GNP+ Central Secretariat
P.O. Box 11726,1001 GS
Amsterdam, The Netherlands
tel. +31 20 689 8218

International AIDS Society
IAS Secretariat
Internet Resources

The Internet, by facilitating discussion and allowing for immediate publication of information, is an invaluable tool for updating and staying abreast of information about the epidemic. HIV/AIDS mailing lists deliver information as e-mail and are an excellent way to keep up with news and information. Subscribe to AIDSNEWS, which distributes federal press releases and daily news summaries, and AIDS, which provides a forum where people concerned with HIV/AIDS share information and ideas. HIV/AIDS newsgroups are a similar source of timely information and ongoing discussions about the epidemic. Browse sci.med.aids and misc.health.aids to stay abreast. The World Wide Web (WWW) provides access to a constantly changing menu of sources of timely HIV/AIDS information. If you are new to the Web, use WWW directories (e.g., Yahoo http://www.yahoo.com/), which offer lists of HIV/AIDS-related and other health-related Web sites. More experienced Web surfers can use WWW indexes (e.g., Lycos
http://www.lycos.com/) to search the WWW and create specialized lists of HIV/AIDS Web sites.


Websites and Search Engines

AIDS BBS List (Norman Brown’s)
http://www.qrd.org/QRD/aids/aids.bbs.list

AIDS & HIV (Einet Search Engine)
http://galaxy.einet.net/GI/health.html

AIDS Info BBS
sprite.berkeley.edu

AIDS Information
gopher://odie.niaid.nih.gov
gopher://hivnet.org

AIDS Information Around Cyberspace

AIDS Legal Referrel Panel

AIDS Mosaic
http://www.thoughtport.com/gallery/resident/AIDSnfo/

AIDS Patents Project
http://patents.cnidr.org/

AIDS Project Los Angeles
http://www.gus.net/care/apla/index.html

AIDS Radiothon
http://www.slip.net/-scmetro/aids.html

AIDS Resource List
http://www.teleport.com/-celinec/aids.shtml

AIDS Resources (Calvin Fleming’s)
http://www.usc.edu/dept/annenberg/cline/asc/stu/calvin/aids.resource

AIDS Resources Listing (University of Wisconsin)
http://www.bocklabs.wisc.edu/duni/aidsresources.html
AIDS Terms Glossary

AIDS Treatment Data Network “The Network”

AIDS Virtual Library
http://www.actwin.com/aids/vl.html

AOL HIV/AIDS Discussion Clubs & Interests/GLCF/AIDS&HIV

The Body
http://www.thebody.com/

Bulletin of Experimental Treatments for AIDS (BETA)
http://gopher.hivnet.org:70/ls/magazines/beta

Centers for Disease Control and Prevention
http://www.cdc.gov/cdc.html

Centers for Disease Control (CDC) National AIDS Clearing House
http://cdcnac.aspensys.com:86gopher://cdcnac.aspensys.com:72listerv@cdcnac.aspensys.com
ftp://cdcnac.aspensys.com/pub/cdcnac

CHAT—Interactive AIDS and Epilepsy
telnet debra.dgbt.doc.ca 3000
telnet 142.92.36.15 3000

Chat Natural Language System (AIDS searches)
http://debra.dgbt.doc.ca/chat/chat.html

Consumer Product Safety Commission
gopher://cpsc.gov

Detroit AIDS Community Library Virtual HIV/AIDS Info Source
http://gopher.libraries.wayne.edu/aids.html

Educational Tech Net
telnet etnet.nlm.nih.gov
telnet 130.14.10.123 login: etnet
FDA BBS (news releases, AIDS information)
telnet fdabbs.fda.gov
telnet 150.148.8.48 login: bbs

FedWorld
http://www.fedworld.gov/

g/l/b/queer Usenet Newsgroups
http://server.berkeley.edu/mblga/netnewswww.html

Global Programme on AIDS, World Health Organization
http://qpawww.who.ch/gpahome.htm

Health and Human Services
gopher://gopher.os.dhhs.gov

Healthnet
http://hpb.hwc.ca/healthnet

Health Resources

HIV/AIDS FAQs (frequently asked questions)

HIVNET/GENA Information Server
http://www.hivnet.org/

HIV Sequence Database WWW Home Page
http://hiv-web.lanl.gov/

International AIDS Society
http://www.ias.se/

International Community of Women Living with HIV/AIDS
http://www.icw.org/

International Council of AIDS Service Organizations (ICASO)
www.web.net/-icaso/icaso/html

Joint United Nations Programme on HIV/AIDS
http://www.unaids.org/
List of U.S. Resources
http://www.bocklabs.wisc.edu/duni/aidsresources.html

Medical Education Information Center (MEDIC)
http://hyvax.med.rth.tmc.edu/gopher://gopher.health.state.ny.us
gopher://selway.umt.edu 700 login: health
telnet selway.umt.edu

Medical Gopher
gopher://gopher.med.harvard.edu
gopher://calmed.med.miami.edu

Medical Resources

National Archives and Records
gopher://gopher.nard.gov

National Health Information Resources Center
http://www.os.dhhs.gov/ (158.70.252.2)

National Institute of Allergy and Infectious Disease (NIAID)
gopher://odie.niaid.nih.gov/ll/aids/

National Institutes of Health
gopher://gopher.niaid.nih.gov:70/00/aids/cdcs

National Library of Medicine (NLM)
http://www.nlm.nih.gov/

OUTline (treatment activism)
http://www.out.org/

Public Health Information Guide
http://128.196.106.42/ph-hp.html

Project Inform
http://www.hivnet.org/inform-www/index.html

Queer Infoserver
http://server.berkeley.edu/mblga/qis/health.html

Queer Resources Directory, AIDS Section
http://www.qrd.org/QRD/www/AIDS.html
gopher://vector.casti.com

gopher://1439.52.1.130

Safer Sex Page
http://cornelius.ucsf.edu/~troyer/safesex.html

Safety and Health
gopher://dewey.tis.inel.gov 2013

University of California at San Francisco AIDS/
HIV Info
http://www.library.ucsf.edu/kr/subs/hiv/index.html

World Wide Web Virtual Library: AIDS
http://www.actwin.com/aids/vl.html

Electronic Bulletin Boards are, unless otherwise stated, free. The listed telephone
numbers are data lines that can be dialed with a modem.

AEGIS_World_HQ
San Juan Capistrano, CA
(714) 248–2836

After Dark
Sarasota, FL
(813) 377–6443

AIDS Info BBS
San Francisco, CA
(415) 626–1246

AtlantaLink BBS
Atlanta, GA
(404) 355–3117

Ban-AIDS BBS
Montgomery, AL
(205) 264–8090

Boston AIDS Consortium SPIN
Boston, MA
(617)432–2511

CESAR
Washington, D.C.
(562) 403–8343
Computerized AIDS Ministries Resource Network
(CAM)
New York, NY
(212) 222–2135

Critical Path AIDS Project BBS
Philadelphia, PA
(215) 563–7160

Drug Abuse Information Monitoring Project
(DAIMP)
Los Angeles, CA
(310) 825–3736

FDA Electronic Bulletin Board
(800) 222–0185

FedWorld
Washington, D.C.
(703) 321–8020

Fog City BBS
San Francisco, CA
(415) 863–9697

Gay and Lesbian Information Bureau (GLIB)
Washington, D.C.
(703) 578-GLIB (4542)

HNS HIV-NET
(800) 788–4118

HRSA DHS-BBS
Washington, D.C.
(301) 443–9308

Labor News
Washington, D.C.
(202) 219–4784

Legalnet
St. Petersburg, FL
(813) 343–0543
Matchmaker Mecca BBS
East Brunswick, NY
(908) 821–1684

Midwest AIDS & HIV Information Exchange
(MAHIE)
Chicago, IL
(773) 772–5958

NCJRS BBS
Washington, D.C.
(301) 738–8895

NIH Information Center
Bethesda, MD
(800) 644–2271
(301) 480–5144 (Maryland only)

OASH BBS
Washington, D.C.
(202) 690–5423

OUTline San Francisco/TheHIVe
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THE AIDS EPIDEMIC: AN OVERVIEW

This Overview section of the *Encyclopedia of AIDS* is designed to introduce readers to the broad sweep of the HIV/AIDS epidemic and, in particular, to the manner in which this volume covers the epidemic's complex social, political, cultural, and scientific dimensions. While the specific entries in the body of the book are organized alphabetically, the Overview enables the reader to trace through particular themes and areas of interest and to see how different entries interrelate.

The Overview encompasses the eight domains covered by the *Encyclopedia of AIDS*: Basic Science and Epidemiology, Transmission and Prevention, Pathology and Treatment, Impacted Populations, Government and Activism, Policy and Law, Culture and Society, and The Global Epidemic.

The introduction to each domain contains a brief synopsis, giving readers unfamiliar with HIV/AIDS the opportunity to obtain a broad introduction to the key points of the epidemic by reading all the introductions sequentially. Each domain also includes a "Perspectives on the AIDS Epidemic" essay that highlights a broad topic of particular importance for that domain.

Basic Science and Epidemiology

Synopsis:

- Acquired immunodeficiency syndrome (AIDS) is not a single distinct disease, but rather a disorder characterized by a severe suppression of the immune system. This immunodeficiency renders the body susceptible to a variety of normally manageable infections, cancers, and other diseases.
- AIDS is caused by the human immunodeficiency virus (HIV), a virus that infects certain cells throughout the body. Most significantly, HIV infects white blood cells of the immune system (particularly T cells, or more specifically CD4+ cells), the role of which is to help clear disease-causing substances from the body.
- AIDS is the name given to a late stage of HIV infection in which there is evidence of significant impairment to the immune system. Because the illness is best understood as a continuum from initial infection to, in many cases, death, the term HIV/AIDS is frequently used.
There are two versions of HIV, both of which can cause AIDS: HIV-1, which has spread throughout the world, and HIV-2, a far less common and somewhat less harmful version largely restricted to West Africa. In the absence of further clarification, the generic term “HIV" almost universally refers to HIV-1, including throughout this volume.

HIV has spread throughout human populations across the globe and is being intensively tracked by health authorities using the tools of the science of epidemiology.

Coverage in the Encyclopedia:
Most of the entries listed in this section emphasize the biochemical workings and the spread of HIV (the virus) rather than medical complications of AIDS (the medical condition resulting from HIV infection). The specific illnesses relating to HIV infection and AIDS are covered below under “Pathology and Treatment.”

The Basic Science entries focus on describing HIV itself, how it causes disease, where it originated, and how it relates to other human and animal viruses (particular the subtype of viruses called retro viruses). This group also includes entries on the various types of cells that comprise the human immune system and how they are affected by HIV and how HIV infection can eventually lead to AIDS.

The Epidemiology entries focus on the study of how disease in general, and HIV in particular, spreads over time through human populations.

Entries on Basic Science
AIDS, Pathogenesis of
Animals
Antibodies
B Cells
HIV, Description of
HIV, Origins of
HIV Infection, Resistance to
HTLV
Immune System
Monocytes and Macrophages
Natural Killer Cells
Retroviruses
T Cells

Entries on Epidemiology
AIDS, Case Definition of
Epidemics, Historical
Forecasting
Geography
GRID (Gay-Related Immune Deficiency)
Seroprevalence
Surveillance
Challenging the Mainstream Consensus: AIDS Dissidents

Perspectives on the AIDS Epidemic: Basic Science and Epidemiology

In the context of the discussion of AIDS, the term dissidents refers to individuals who oppose mainstream or officially sanctioned understandings of the epidemic (including those views presented throughout this encyclopedia). Such dissidents have faced many challenges, from the skepticism of individual scientists and the probing questions of reporters, to public demonstrations by AIDS activist groups. For dissidents, varying issues are in contention, including the probable cause or causes of the syndrome; the disease’s geographic origins; the politics and economics of research and treatment; the value of AIDS education, safer-sex, and blood-testing programs; and the role of the media in establishing consensus. Although many AIDS dissidents share certain attitudes and opinions, they by no means form a unified force. They may be described by several overlapping categories: dissenters regarding the cause of AIDS, political dissidents, proponents of alternative treatments, and proponents of mental and spiritual approaches to healing and prevention.

The most radical dissidents are those who have disagreed with what they call the “HIV-AIDS hypothesis”—the contention, which they consider unproven, that HIV is the cause of AIDS. Included among them are a number of prominent academics, most notably microbiologist Peter H. Duesberg of the University of California at Berkeley and Kary Mullis, the 1993 Nobel laureate in chemistry. Since 1989, AIDS dissidents have held a number of international conferences to discuss and promote their views. An advocacy organization, The Group for the Scientific Reappraisal of the HIV-AIDS Hypothesis, was established in 1993.

The most widely proposed alternative to the HIV-AIDS hypothesis is a multifactorial model that ascribes the infections usually attributed to AIDS to combinations of factors, including recreational drug abuse, use of antibiotics, multiple sexually transmitted diseases, impure blood products, malnutrition, and other factors that can cause immunosuppression.

Another group of dissenters, who generally accept that HIV causes AIDS, might be called political dissidents. In response to what was perceived as inadequate official reaction to the AIDS crisis, a network of local initiatives and political action groups emerged from the gay community during the 1980s. Highly critical of government and scientific policies and of the role of large pharmaceutical companies in the epidemic, these organizations have advocated for improved AIDS care and research, freer access to experimental treatments, and increased emphasis on holistic and self-empowerment approaches. Among the most vocal of these groups have been the various chapters of ACT UP, a grassroots AIDS organization that has gained public attention for its street demonstrations and civil-disobedience campaigns. Political dissidents have also protested against restrictions on the civil rights of those who have tested or who are suspected of being HIV-positive.

Proponents of holistic and alternative therapies form a third group of dissidents. Alternative therapies used to treat AIDS-related conditions have included traditional Chinese medicine (including acupuncture), macrobiotics, nutritional and vitamin therapies, herbalism, and naturopathy. Health Education AIDS Liaison (HEAL) in New York, Positively Healthy in the United Kingdom, and other groups provide advice and
holistic and alternative therapies to people with AIDS. These organizations are skeptical of official AIDS policies, in particular of predictions of high fatality rates for those testing HIV-positive. They have attacked the use of nucleoside analog drugs such as azidothymidine (AZT), saying that these drugs are ineffectual and toxic and that they produce side effects similar to AIDS symptoms.

Proponents of mental and spiritual approaches constitute the final group of dissidents. Advocates of meditation and visualization have proposed a variety of mental techniques to strengthen the immune system, and they acknowledge the new science of “psychoneuroimmunology” for its research into the effects of mind-body interaction on health. Some regard mental factors, such as attitude and psychological outlook, as especially important in the genesis of AIDS in individuals.

Separate from other groups of dissidents are those who might be called alarmists. They accuse the government of minimizing the risk of HIV transmission and have suggested the possibility of contagion by insects, casual contact, or proximity. Some alarmists have predicted a world plague of apocalyptic proportions. Other single-issue dissidents question specific aspects of orthodox opinion, such as the possibility of a so-called heterosexual epidemic in the United States. Some investigators have questioned the alleged African origins of AIDS or that AIDS as such even exists in Africa, regarding deaths ascribed to AIDS as actually caused by a combination of malnutrition; drug poisoning; and endemic diseases, many of them curable.

Publication of dissident writings has been scattered and sporadic, and even the most eminent writers have encountered difficulty in airing their views in traditional media. As a consequence, several dissident magazines and newsletters were founded, including *Rethinking AIDS* in the United States and *Continuum* in the United Kingdom. In the popular press, the gay newspaper *New York Native* and the music magazine *SPIN* consistently covered unorthodox views on AIDS. Addressing why dissenting views on AIDS have been marginalized, dissidents have suggested that medicine relies as much on emotion, cultural assumptions, politics, and economics as it does on science. Today, the prevailing medical model is one of infection, developed in the nineteenth century; other systems of medicine, such as homeopathy, pay as much attention to the characteristics and resistance of the host as to those of the individual pathogens.

Critics of medical orthodoxy have pointed out that the current approach of isolating a single infectious agent and developing a drug to overpower it has created problems, including the dismissal of multifactorial hypotheses, the unwarranted use of toxic medicines such as AZT, and the emergence of antibiotic-resistant pathogenic strains. Some regard the medical establishment’s failure to deal effectively with AIDS as further evidence that a reappraisal of western health care is in order. AIDS is thus seen as a crisis not only for public health but also for medical science. Many in the West, dissatisfied with the cost and ineffectiveness of conventional medicine, have wholly or partly abandoned it for homeopathy, naturopathy, and traditional Chinese medicine.

Many dissidents propose that the current “infection model” of AIDS be superseded by a “pollution model.” In the latter approach, AIDS is examined not as a single disease, but as a complex of diseases generated by the stresses of modern lifestyles, social conditions, and medical practices. These stresses especially affect the risk groups to which AIDS remains largely confined. This model also suggests that genetic predispositions may affect the development of AIDS in certain individuals.
In general, the critiques of AIDS dissidents have been resisted by both government and mainstream science. AIDS dissidents remain marginalized by what they contend is a premature consensus encouraged by political and economic, rather than scientific, factors.

IAN YOUNG

Transmission and Prevention

Synopsis:

• HIV is transmitted by certain specific behaviors involving the exchange of bodily fluids between people. Unlike many other diseases, HIV is not transmitted through routine casual contact, through the air, or through insect bites.
• Sexual activities can transmit HIV when they involve direct contact between the HIV-infected bodily fluids (such as semen, vaginal secretions, and blood) of one person and the mucous membranes (such as in the vagina, rectum, and mouth) of another. This transmission can be reduced by avoiding these behaviors or by proper use of barriers such as condoms and dental dams.
• Needles used to inject drugs can transmit HIV when they are used by more than one person. Needles should never be shared, but if they are shared they should be thoroughly cleaned between uses.
• HIV can be transmitted from person to person through the transfusion of blood and blood products. However, routine screening for HIV of the blood supply has dramatically reduced this mode of transmission, at least in the developed world.
• HIV can be transmitted from mother to fetus/baby while it is still in the uterus, during the delivery process, and through breast-feeding. There is strong evidence that use of antiviral medications during pregnancy can reduce maternal transmission of HIV.
• People become infected with HIV due to behaviors, not because of membership in any particular “high risk group,” making HIV infection a possibility for almost everyone but an inevitability for almost no one.

Coverage in the Encyclopedia:
The entries in this section emphasize behaviors rather than risk groups. Many of these entries have companion entries for specific types of individuals (e.g., Gay Men; Hemophilia, People with; Injecting Drug Users; etc.), all of which are listed in the section below on “Impacted Populations.”

The entries on sexual transmission and prevention cover the specific sexual behaviors and the main bodily fluids that are most frequently responsible for HIV transmission. Other entries cover sexual acts that rarely, if ever, cause HIV transmission but that cause concern among many people. The entries on sexual transmission also cover the social behaviors and attitudes within which sexual transmission of HIV occurs. In addition, these entries also include coverage of the most important approaches used to prevent the sexual transmission of HIV.

The entries on needle sharing among injecting drug users (IDUs) discuss the various mechanisms of IDU transmission. They also cover related topics concerning the social
and policy contexts within which drug use occurs and how injecting drug use can be made less risky.

Other entries cover maternal transmission, transmission through blood and blood products, and accidental exposures. Several important general prevention strategies are also covered.

Entries on Sexual Transmission and Prevention

Abstinence
Anal Intercourse
Bisexuality
Child Sexual Abuse
Condoms
Dental Dams
Kissing
Lubricants
Manual-Digital Sex
Masturbation
Monogamy
Mouth
Oral Sex—Anilingus
Oral Sex—Cunnilingus
Oral Sex—Fellatio
Public Sex Environments
Safer Sex
Safer-Sex Education
Saliva
Semen
Sex Work
Sexual Assault
Sexually Transmitted Diseases
Vaginal and Cervical Secretions
Vaginal Intercourse

Entries on Injecting Drug Use Transmission

Drug Outreach Projects
Harm Reduction
Injecting Drug Use
Injecting Drug Use, Subculture of
Needle-Exchange Programs

Entries on Other Means of Transmission and Prevention

Blood
Blood Transfusions
Dentistry
Interventions
Maternal Transmission
The aids epidemic

Migration
Transmission, Misconceptions About
Tattooing, Piercing, and Scarification
Transplantation
Universal Precautions

The Intersection of Host and Virus: Risk Factors for HIV Infection

Perspectives on the AIDS Epidemic: Transmission and Prevention

The primary mission of HIV research is simple: to determine how HIV is spread, causes disease, and can be treated in human beings. Although it is true that many advances have been made in each of these particular areas of research, it is also true that research can never yield 100 percent accurate results and there will always be exceptions to every rule. For example, research has yet to determine why some people infected with HIV progress faster than others. Likewise, research has yet to yield a vaccine or cure that will be effective in everybody. The same goes for HIV transmission: some people are more prone to becoming infected with the virus than others.

Despite the fact that researchers have been able to isolate HIV in virtually every fluid secreted by the body—including tears, saliva, urine, blood, semen, mucus, and vaginal secretions—HIV still remains, relatively speaking, a virus that is not easily transmitted from one person to another. HIV’s ability to successfully leave one person’s body and enter another’s is highly dependent on secondary factors. These secondary factors—called risk factors—are based on both biological and behavioral characteristics.

The biological factors associated with HIV transmission are numerous and complicated. Characteristics on which a determination of the probability of sexual transmission depends include the concentration of HIV in the fluid, the integrity or relative vulnerability of involved mucous membranes (such as those inside the anus, vagina, or mouth), the duration of exposure, and the strain of virus transmitted. For example, HIV can be found in saliva, tears, blood, breast milk, semen, urine, and vaginal and anal secretions. The level of HIV in each of these fluids varies greatly, however. HIV levels are high in blood, semen, and breast milk; moderate in anal and vaginal secretions (although higher for the latter during menstrual periods); and low in saliva, tears, and urine. Thus, the type of bodily fluid someone comes into contact with is in itself a significant biological characteristic.

Of course, HIV is not transmitted simply by coming into contact with an HIV-infected fluid; the fluid must enter another person’s body to transmit HIV. The way in which the fluid enters the body is commonly referred to as the route of transmission and is yet another important biological characteristic that may be associated with HIV transmission. HIV-infected bodily fluids can be swallowed, accepted into the vagina or rectum, or injected directly into the bloodstream. HIV is much more likely to directly enter the body and cause infection through some routes more than others, however.

Based on what is known about these biological characteristics, epidemiologists have been able to devise calculations to determine the level of risk, or likelihood, of becoming infected with HIV. By considering both the type of bodily fluid and the route of potential transmission, it is possible to assess someone’s general level of risk of being infected
with HIV. Levels of risk have been assessed for every possible form of human contact. For example, shaking hands or hugging is not associated with any sort of risk. On the other hand, injecting drug users who share needles bear a very high risk of HIV transmission, given that HIV-infected blood often remains in or on the hypodermic needle and can easily be injected directly into another person’s bloodstream.

Each type of sexual contact has its own level of risk, and many people’s sexual lives are structured so that some risk of HIV infection exists. Yet, the definitive level of risk associated with each and every sex act cannot always be calculated. For example, anal sex—in which HIV-infected semen comes into contact with tiny abrasions of the anal wall—is highly risky for HIV transmission. Oral sex—in which semen or vaginal fluids are taken into the mouth and/or swallowed—is considered a less likely route of HIV transmission. A single, penetrative sexual contact with an infected partner does not always lead to infection, because HIV infection occurs only if biological characteristics are suitable. Repeated exposures increase the odds for creating suitable conditions for infection.

Behavioral factors are directly related to biological factors. Because many of the latter do not occur inadvertently but can be avoided by way of behavioral change, behavior plays a large role in the continual spread of HIV. Examples of behavioral characteristics include whether or not individuals practice abstinence, use condoms, abuse drugs or alcohol, and use clean hypodermic needles.

When behavioral characteristics are calculated along with biological characteristics, the riskfactor equation becomes more complete. For example, someone who uses a condom every time he or she engages in anal or vaginal sex is much less likely to become infected with HIV than someone engaging in similar sex acts without a condom. Likewise, an injecting drug user is much less likely to become infected with HIV if he or she cleans a previously used hypodermic needle before using it to inject drugs again.

There are, however, cases in which both biological and behavioral characteristics are less definitive. Oral sex, for example, is generally associated with a relatively lower biological risk of HIV transmission. Many HIV-prevention experts argue that condom use during oral sex is still necessary, despite the low risk. Yet, many are reluctant to practice safer oral sex with a condom.

Unlike biological risk factors, which are determined based on anatomic and physiological knowledge and for which specific HIV-prevention measures can be devised, behavioral risk factors are often the most difficult to calculate and control. Despite the knowledge that condom use can prevent HIV transmission, many men and women continue to have unprotected sex. Perhaps this reality reflects the greatest shortcoming of scientific research: that, in addition to the fact that no scientific principle will prove true for everyone, no one type of behavior-modification approach will be effective in preventing the spread of HIV.

TIM HORN AND ANDRES SCIOLLA
Pathology and Treatment

Synopsis:

- As a syndrome rather than a single distinct disease, AIDS encompasses a number of distinct forms of pathology (illness).
- Most AIDS-related pathologies are caused by cancers or by opportunistic infections by bacteria, viruses, fungi, protozoa, or other microbes that the body cannot combat because HIV has so seriously damaged the immune system.
- Other AIDS-related pathologies result from the direct infection by HIV of cells in the nervous or digestive systems. Still other medical conditions are the undesirable side effects of the powerful toxic drugs used to combat HIV and its associated illnesses.
- Some, but not all, of the pathologies associated with HIV/AIDS are officially recognized as AIDS-defining illnesses, which means that when they occur in a person with HIV, that individual then has a formal diagnosis of AIDS. A diagnosis of AIDS can also be made on the basis of a low count of CD4+ cells, according to criteria used in the United States.
- Treatment for HIV/AIDS has three main dimensions: attacking the virus itself, strengthening the immune system, and controlling AIDS-related cancers and opportunistic infections. There have been significant advances in all three types of treatment since the start of the epidemic.
- As of 1997, there is no proven “cure” for AIDS, in the sense of a single treatment that could eliminate HIV from the human body or reverse the damage done by HIV to the immune system. There is also no effective vaccine to prevent new infections.

Coverage in the Encyclopedia:
The Pathology entries cover the various types of HIV-related illnesses, including those that are and are not AIDS-defining. Many of the conditions that are AIDS-defining illnesses have their own entries or are cross-referenced to a generic entry in which several related conditions are discussed (such as enteric diseases and fungal infections). Typically, the treatment of any given form of pathology is briefly discussed in the entry that covers that illness.

A distinct subfield of illness relates to the damaging psychological impact of HIV and AIDS, which requires specialized treatment. While certain types of psychological reaction can be considered normal, rather than pathological, responses to life stress, they are included in this section because they can be detrimental to overall mental health.

The Treatment entries review the wide range of types of treatment, both conventional and unconventional. Some treatments, notably antiviral medications and vaccines, are designed to target HIV itself. Other treatments seek to boost the immune system to minimize or eliminate the effects of HIV. In addition, these entries include information about the means by which treatments are developed and administered.

Entries on Physical Pathologies

AIDS, Case Definition of
AIDS, Pathogenesis of
AIDS-Related Complex (ARC)
Bacterial Infections
Blood Abnormalities
Cervical Cancer
Cytomegalovirus (CMV)
Dementia
Enteric Diseases
Fungal Infections
Hepatitis
Herpes
Human Papillomaviruses
Kaposi’s Sarcoma (KS)
Kidney Complications
Long-Term Survivors and Non-Progressors
Lymphadenopathy
Lymphoid Interstitial Pneumonia (LIP)
Lymphoma
Malnutrition
Mouth
*Mycobacterium avium* Complex
Nervous System, Central
Nervous System, Peripheral
Pain
*Pneumocystis carinii* Pneumonia (PCP)
Progressive Multifocal Leukoencephalopathy (PML)
Seroconversion
Skin Diseases
Toxoplasmosis
Tuberculosis
Wasting Syndrome

Entries on Mental Health

Bereavement
Counseling
Death and Dying
Mental Health
Suicide and Euthanasia
Support Groups
Testing

Entries on Treatment

Antioxidants
Antiviral Drugs
Caregiving
Chinese Medicine
Clinical Trials
Complementary and Alternative Medicine
Cure
Imagine the pain and anguish of being a person with AIDS (PWA) and of knowing early test results of promising new therapies, only to be told: “Sorry, this drug is not available yet.” Early in the AIDS crisis, patients were forced to wait for years and years for the system to approve even the most marginally effective HIV drug, azidothymidine (AZT). A sense of tragedy and outrage grew from the spectacle of friends and lovers dying while promising results about the latest breakthroughs spread instantly through an electronic rumor mill.

AIDS treatment was, and still is, a battle both against the virus and against bureaucracy. In the early years, there was no medical triage, but rather the opposite: the drug trial system weeded out the sick, opting instead to test the latest drugs only on the healthy. The drug manufacturers decided it would be easier to keep the well healthy rather than to honor medicine’s traditional goal of healing the sick.

From the outrage felt by PWAs there grew a movement for change. Early on, groups of gay men formed support systems and information networks. Everyone working in these areas knew that two identical patients with identical maladies could have completely different outcomes; one might live and one might die based solely on what the patient and doctor knew at the time. By the end of the 1980s, new treatment solutions were at hand for life-threatening illnesses, but they remained blocked by lack of knowledge and, even more so, by lack of access.

Many PWAs and their friends decided that they were no longer going to sit back and do nothing. Project Inform, the Treatment Action Group, and certain chapters of ACT UP such as New York, Golden Gate (in San Francisco), and Philadelphia nurtured a new breed of activism: treatment activism. Some treatment activists set out to infiltrate the research system and the U.S. Food and Drug Administration (FDA). Others preferred to stay on the outside, agitating with street theater designed to generate media coverage.

At first, the system would not yield: how could patients possibly know as much as doctors? But in time, treatment activists gained a voice in the clinical trials networks, formed advisory boards at several major research institutes, and even attended FDA drug advisory panels. A system that once took seven to 10 years to approve a drug pared down that time to four years or less. Thanks to a mutual sense of urgency, there are more than a
dozen new therapies on the shelves. New research and drug development are fueled by a lucrative market, and where new drugs cannot meet a need quickly enough, underground treatments help the savvy survive. Indeed, many owe their lives to the underground buyers’ clubs, which were formed to circumvent government bureaucracy.

PWAs and their friends have also taken hold of complex research problems. For instance, the Immune Based Therapies Think Tank was begun in San Francisco to generate new protocols and collaboration toward restoring battered immune systems. Setting an amazing historical precedent, the sick, whom the system had left to die, found a way to catalyze some of the most aggressive immunology research of the past 50 years. The think tank turned out concepts and protocols concerning cell therapy, gene therapy, and cytokine administration. Even more, it forced collaboration between researchers, overcoming one of the most damning obstacles to AIDS research: infighting and petty feuds between scientists. Finally, after many years, some scientists realized that it was more important to find a cure for AIDS than to publish and get credit for small academic advances.

Individuals with AIDS were told over and over again with certainty that they were going to die. The only way out of the trap was for PWAs to create alternative “certainties”—that is, to find and establish other reasonable paths that could lead to survival. Most such paths were dead ends, but that did not stop treatment activists. After reaching several such dead ends, the survivors simply developed new strategies, changing the path as they went along. Living a life that required continuously changing treatment strategies may have been difficult, but there was no alternative but death.

For many treatment activists, finding a way to increase and refine treatment options became the prize. Still, uncertainties persisted. How were these new treatments to be used? How could it be ascertained that these drugs worked? What was adequate proof, and who would decide? In the 1990s, incredible debates took place about whether or not it was necessary to speed up or slow down new drug approval. The compromises between treatment activists that eventually emerged as consensus were often a tricky mandate to approve new therapies, even marginal drugs, as quickly as possible while forcing drug companies to improve efficacy data. Fortunately, as far as can be told, no drug has yet been approved that later maimed or killed its users. Yet, this could well have happened—and there are some who say that AZT could be described as harmful to its users. But for many treatment activists, the prize was worth the risk.

Taking action has become a survival strategy for many long-term survivors of AIDS. Such action must be carefully planned and executed. It is often risky, usually a matter of life and death. The experiences of those who have died, as borne witness to by those who have survived, have proved again and again the treatment activist axiom that “Action=Life.”

JEFF GETTY
Impacted Populations

Synopsis:

- Early in the epidemic, AIDS in the developed world was closely associated with the subgroups in which it was initially identified, particularly gay men, injecting drug users, hemophiliacs, and recipients of blood transfusions. However, it is now understood that HIV transmission is related to behaviors rather than to membership in any particular class, category, or group.
- Nonetheless, because some risk behaviors are disproportionately common among members of certain groups, the level of HIV infection has remained higher in some subpopulations than among the general population.
- Infection rates also remain higher in certain subpopulations because the members of many of these groups tend to interact with one another more than with those outside the group. Thus, when members of these subpopulations engage in risk behaviors, they are disproportionately likely to encounter sexual or drug-using partners who are HIV-positive.
- While HIV/AIDS affects every individual differently, certain patterns can be discerned in its overall medical and social impact. These patterns correlate to certain characteristics such as gender, age, race/ethnicity, sexual orientation, occupation, income, and place of residence.

Coverage in the Encyclopedia:
The entries on Impacted Populations focus on the major social groupings that have been affected by the HIV/AIDS epidemic in a distinct and identifiable manner. Any given individual may belong to several different categories (e.g., age, gender, race/ethnicity), and many entries discuss important intersections between categories (e.g., African American gay men, Latinas living in poverty, etc.). The entries tend to focus on groups in the United States, but much of what is discussed may be generalized to similar groups elsewhere, particularly in other parts of the developed world. Specific impacted populations outside the United States are discussed in the entries on the various world regions.

Many of the individuals in these populations may be associated with particular behavioral risks for HIV infection, which are covered above in the section on “Transmission and Prevention.”

Other entries in this section relate to prejudicial social attitudes toward specific groups. These attitudes may influence the way in which members of these groups experience the HIV/AIDS epidemic and the way in which they are treated by society at large.

Entries on Impacted Populations

Adolescents
- African Americans
- Asian and Pacific Islander Americans
- Babies
- Bisexuals
- Children
College and University Students  
Couples  
Developmental Disabilities, People with  
Disabilities, People with  
Emergency Workers  
Families  
Gay Men  
Health Care Workers  
Hemophilia, People with  
Heterosexual Men  
High School Students  
Homeless Populations  
Injecting Drug Users  
Latinos  
Lesbians  
Mental Illnesses, People with  
Suburban and Rural Populations  
Sex Work  
Transgendered People  
Women  

Entries on Social Attitudes  

Discrimination  
Gender Roles  
Homophobia  
Public Opinion  
Racism  
Sexism  
Stigma  

Life in the Maelstrom: Living and Working Amid the AIDS Epidemic  

Perspectives on the AIDS Epidemic: Impacted Populations  
The landscape of my life, personal history, memories, and dreams are all littered with the corpses and ghosts of loved ones, clients, colleagues, and fellow members of my tribe and community who have died in this plague. Being a middle-aged, HIV-positive gay man living and working as a psychotherapist in Manhattan’s Chelsea neighborhood—a ground zero of the AIDS epidemic in North America—there is no way it could be any different. I clearly remember that morning in July 1981, walking back to my house in the, unknowingly, already stricken Fire Island Pines, reading that ominous first story about a rare cancer affecting gay men in Los Angeles and New York. My immediate reaction was anger and skepticism. I dismissed the news story as some kind of hysterical, homophobic hype perpetrated by the medical establishment and the media in an attempt to frighten gay men into conforming to mainstream sexual norms.
How naive and oblivious all of us were, not knowing that an infectious agent had already begun its deadly journey, spreading through hundreds of thousands of people, framing our lives. Since the early 1980s, when AIDS began to decimate the gay community, I have been surrounded by illness, death, and grief.

The first few deaths of my friends and clients were terribly traumatic. Even as I grieved and went to the funerals and memorial services, I grew angry and frustrated that these men’s lives had been cut short. Some of them were tremendously gifted and creative, and the loss seemed unspeakably tragic. Among those who passed away was my oldest brother, Henry, who died in my apartment in 1984. My best friend and colleague in private practice, Luis, died of AIDS in 1989. Six men in my apartment building died of AIDS in the early 1990s, as have more than 100 of my clients, while dozens more are now symptomatic or in the hospital. In late 1994, four of my closest friends and, hardest to bear, my beloved partner, Lee, died of AIDS. As a 45-year-old AIDS widower who has been infected with HIV since the 1970s but remains healthy on a combination of antiviral drugs, I do not have the luxury of assuming that I am living through the middle, rather than the twilight, of my life.

All this has been nothing like what I had expected when training to be a psychotherapist. Back then, I had certain young and hopeful ideas about the potential of human beings, within a normal lifespan, to grow in self-awareness. My job, as I saw it then, was to help them make changes that would allow them to lead happier lives. But by the mid-1980s, I suddenly found myself with a clientele made up largely of gay men who were either symptomatic with AIDS or anticipating the onset of symptoms, many of them under the age of 40.

This required me to learn a whole new set of coping and clinical skills. All I really knew about counseling clients and their families at the end of life was Elisabeth Kubler-Ross’s work on the stages of death and dying. Back then, I remember being surprised and annoyed when my friends or clients refused to follow the predictable, linear pattern she had laid out.

Without realizing it, I romanticized death and unconsciously glorified each of the dying people I knew either personally or professionally. I wanted to see them as noble and worthy of my care because of their near death, and I was constantly brought up short because people die in character. I did not yet want to see that a self-involved man who became sick with AIDS might very well handle his illness narcissistically and die the way he had lived, thinking only of himself. I had to learn that I was not going to like someone simply because he was dying, and that death does not necessarily transform people for the better.

Hollywood has pumped us up with a sanitized, sentimental version of death. Everyone is gathered around the dying person’s bedside. Fences are mended, old wounds patched up. Then the dying imparts a last jewel of wisdom before a gentle closing of the eyes. There is no shrieking with fear, no groaning from intolerable pain, no dying alone in an impersonal hospital bed, no homophobia. I have seen otherwise supportive families have a hard time with an AIDS-related death. Lee’s parents would not come to see him before he died. They could not bear to see their beautiful, 32-year-old son wasting away, so they put their own needs before his. This does not make them bad. It is just a sad fact that we do not always rise to the occasion, even when we are confronted with the finality of death.
Over the years, burnout has turned into gratitude that I am alive. Every day, I seek to be as viscerally and emotionally present as possible. Why waste a minute? I find my work especially meaningful. What a gift it is to be able to connect in this extraordinary way with so many good souls! So instead of feeling in jeopardy of burning out, I am thankful to have had the privilege of accompanying Lee, friends, and clients on the last journey of their lives. I have twice been the last surviving individual coordinating care for a dying friend. Luckily I am making new friends, and a few of my very old friends are not infected. Yet I still worry at times that when my time comes there will not be anybody left to care for me. Is this paranoia, or a completely rational fear in the face of this neverending plague?

When I work with clients with HIV/AIDS, I try to help them find a hope that is balanced by a realistic acceptance of what is happening to their bodies and lives. And this is exactly what I must try to do each day in my own as well.

MICHAEL SHERNOFF

Government and Activism

Synopsis:

- AIDS first emerged among populations that are politically disadvantaged, socially marginalized, and partially hidden, such as gay men and injecting drug users. As a result of the low societal status of the earliest people with AIDS, the responsiveness of government institutions was limited during the earliest years of the epidemic.
- The United States has a system of government in which power is shared by executive, legislative, and judicial authorities on both the federal and state levels. This system has created a wide range of governmental responses to HIV/AIDS.
- In general in the United States, governments in heavily impacted cities and states responded more quickly and decisively than national authorities in the early years of the epidemic. Likewise, government institutions controlled by the Democratic Party have generally been more engaged with HIV/AIDS issues than those controlled by the Republican Party.
- In response to governmental and societal indifference and hostility, many people with HIV/AIDS became political activists by forming protest groups such as ACT UP and launching high-profile demonstrations that made use of innovative strategies to attract media attention.

Coverage in the Encyclopedia:
The Government entries of the Encyclopedia of AIDS focus on the general political process and on specific institutions of government in the United States. The response of government in other countries is covered in the entries on the various world regions.

The Activism entries focus largely on ACT UP, the flagship organization of AIDS activism in the United States and elsewhere. Activism before the founding of ACT UP in 1987 is also covered as are forms of activism that occurred in tandem with or in reaction to that carried out by ACT UP. A variety of specific activist strategies and approaches are also covered.
Entries on specific policy and legal issues are discussed in the section on “Policy and Law.”

Entries on Government

Congress, U.S.
- Court Cases
- Legislation, U.S.
- Political Parties, U.S.
- Politicians and Policy Makers, U.S.
- Presidency, U.S.
- State and Local Government, U.S.
- United States Government Agencies

Entries on Activism

ACT UP
- Demonstrations and Direct Actions
- Gay and Lesbian Organizations
- Gay Rights
- Marches and Parades
- Media Activism
- Professional Organizations
- Service and Advocacy Organizations
- Symbols
- World AIDS Day

The High Price of Homophobia: HIV Prevention Education

Perspectives on the AIDS Epidemic: Government and Activism

Discrimination is not only a social concern, but also a health-care concern. In the fight against AIDS, homophobia has been a serious barrier to HIV prevention education. In the United States, homophobia permeates social attitudes regarding sexuality and sexual behavior. Because of the strong association with gay and bisexual men at the beginning of the AIDS epidemic, homophobia has had many negative effects. Among these have been inadequate HIV prevention efforts in schools and the undermining of public health initiatives for HIV prevention and research appropriate to high risk populations.

The link between societal homophobia and AIDS was established early in the epidemic, when AIDS was still known as GRID (Gay-Related Immune Deficiency). Only later, when the disease was found to be in other populations, including women, was the name changed to AIDS.

Despite the proliferation of HIV infection and AIDS throughout the 1980s, then-President Ronald Reagan did not utter the word AIDS publicly until more than six years into the epidemic. Nor did President Reagan and his administration allocate sufficient funds to fight this preventable disease. During that period, violence toward gay men and lesbians increased dramatically. In such an atmosphere, the gay and lesbian community,
as well as public health workers and researchers, had to struggle for access to even small amounts of funding.

While AIDS is a behaviorally based disease, it is caused by more than just the behaviors of people who engage in unprotected sex and needle-sharing. AIDS is also caused by the discriminatory behavior of individuals and governments. We know that gay youth, for example, are at high risk for HIV infection: by June 1996, more than 10,000 cases of AIDS had been diagnosed among men under age 25 who had acquired HIV through sex with other men. Yet, in response, we still teach gay youth to be ashamed of who they are instead of affirming them at a very vulnerable stage of their development.

In the United States, we teach several clear lessons through our laws: gay and lesbian lovemaking is a criminal act in nearly half the states; lesbian and gay relationships are unworthy of legal recognition; in more than three-quarters of the states, the civil rights of lesbians and gay men have no legal protections; gays and lesbians are unfit for military service; and gay and lesbian issues are forbidden in most classrooms. To turn around the behaviors that lead to HIV infection, then, we have to take a hard look at the societal prejudices that foster HIV infection.

As a society, we condemn promiscuity among gay men, but then tell same-sex couples who desire to make a commitment to each other that they are somehow a threat to the family. The U.S. Congress has added to the burden of the fight against AIDS when it voted overwhelmingly to prohibit the federal government from recognizing same-sex marriage through its so-called “Defense of Marriage Act.” In essence, the lawmakers said to the gay and lesbian community that a stable, monogamous relationship between partners of the same sex has no value in the United States. As a society, we also say that we are against unfair discrimination and prejudice, but most institutions refuse to take the steps necessary to relieve the atmosphere of anti-gay bigotry that permeates many settings. This devaluing of gay men and lesbians discourages stable relationships and invites discrimination and violence against people perceived as second-class citizens. Yet, when gay and lesbian people object to homophobia and discrimination, they are often told that they are causing a “disruption.”

There are times when we need disruptions. We need to disrupt a status quo that accepts ignorance about human sexuality. We need to challenge the morality of anti-gay bigots, instead of allowing them to label all lesbians and gay men as “immoral.” In the AIDS crisis, the number one factor that helps people—young or old, gay, lesbian, bisexual, or heterosexual—to protect themselves and others against HIV is giving those people a sense that they have a bright and productive future. People must be told that they have a future and a chance at a good life. If they do not, how can they be persuaded to put on a condom, to stop drinking, to stop injecting drugs? Yet many lesbians and gay men are being sent the message that the future is going to be a lot more difficult, simply because of whom they love. Until society addresses some of these underlying barriers to HIV prevention, it cannot hope to get it under control.

JOYCE HUNTER
Policy and Law

Synopsis:

- HIV transmission typically occurs as part of sexual or drug-using activities that are highly personal and often socially sanctioned and/or illegal. Such activities are among the hardest to influence by policy and law.
- The making of policies and laws to control the spread of HIV frequently has pitted two important goals against each other: preserving the civil liberties of people with HIV versus protecting the general public health. Liberals have generally emphasized the need to insulate people with HIV/AIDS from discrimination, while conservatives have often framed the epidemic as a danger to the general population resulting from social decay and personal immorality.
- It has been hypothesized that there are two major and largely incompatible approaches to HIV policy- and lawmaking. The “contain-and-control strategy” focuses on the coercive power of the state to force compliance with laws, while the “cooperation-and-inclusion strategy” relies on the participation of all heavily impacted communities. Different approaches may be appropriate for different policy challenges.
- Another major fault line in policy- and lawmaking has been between the “harm-elimination” approach, which seeks to strengthen people’s ability to abstain from all risk behaviors, and the “harm-reduction” approach, which tries to tackle individual risk behaviors.

Coverage in the Encyclopedia:
Policy and law issues cannot be separated from one another, because many policies are clarified through the legal system and many laws are implemented by means of administrative policies. Policy can be created by both governmental and non-governmental bodies; laws begin as legislation and are subsequently interpreted by courts. The entries in this section focus largely on the United States, which has in many ways served as the worldwide model for HIV/AIDS policy and law. Specific dimensions of policy and law in other countries are discussed in the entries on the various world regions.

Entries on Policy and Law
Abstinence
Confidentiality
Conspiracy Theories
Contact Tracing and Partner Notification
Correctional System
Court Cases
Disclosure
Discrimination
Economics
Educational Policy
Ethics, Personal
Ethics, Public
Family Policy
Double Discrimination: Women with HIV/AIDS

Perspectives on the AIDS Epidemic: Policy and Law
Throughout the world, women suffer from the stigma and deprivation of second-class citizenship based on their sex. In the case of HIV-positive women, this discrimination is compounded by social responses to their HIV status. Thus, particularly in developing countries, HIV-positive women may be especially subject to violations of their sexual and reproductive rights.

Depending on social factors, a husband may legally force his wife to suspend or significantly alter her sex life. For instance, an HIV-positive woman may be forbidden to have children. Often, HIV-positive married women are abandoned by their husbands, with no legal or economic recourse. In some parts of the world, the widow of a man who dies from AIDS loses her property and may be abandoned by her family. Particularly in Africa and Asia, many such widows must generate income from prostitution or from the prostitution of their children.

In many countries, HIV-positive women have little or no access to family planning centers. Pregnant HIV-positive women living in countries where abortion is criminalized may be forced to seek unsafe and illegal abortions, which can jeopardize their lives. HIV-positive women frequently must submit to sterilization or other family planning methods that they have not freely chosen.

In many societies, women’s sexual rights and sexuality remain unrecognized or misunderstood, often owing to cultural and religious values. Practices such as female genital mutilation, early and compulsory marriage of girls, denial of available treatments, and sexual abuse and rape of girls and women create high risks of female HIV infection.

Poverty in developing countries continues to affect more women and children than it does men. Poverty also increases the vulnerability of these women and children to HIV infection. Unemployment and low salaries perpetuate the economic subordination of women and children, and in numerous countries, members of both groups must take up sex work in order to survive. Drug consumption frequently accompanies prostitution, and both increase the risk of HIV infection: sex workers often cannot ensure their clients’
practice of safer sex nor their own or their clients’ use of sterilized syringes and needles. In addition, the number of street children, many of them girls, increases as poverty levels escalate. These children are exposed to violence, coercion, and abuse and in many instances become infected with HIV, yet they have little or no access to treatment.

At the International Conference on Population and Development held in Cairo, Egypt, in 1995, reproductive rights were recognized globally. When the conference met in 1996 in Beijing, China, the majority of the world’s nations extended that recognition to sexual rights (although not sexual orientation).

MABEL BIANCO

Culture and Society

Synopsis:

• The HIV/AIDS epidemic has evoked a wide variety of responses in the realms of culture and society. Such powerful issues as illness and death, pain and loss, hope and despair have been particularly relevant for the creative arts and for religious groups.

• Cultural responses to the epidemic have been closely associated with gay men, the population that was earliest and perhaps most heavily impacted by HIV/AIDS. While much of the culture of AIDS is indistinguishable from that of gay male culture, however, many other voices have been heard and influences felt.

• Religious groups typically have extended existing general doctrines and beliefs about sexuality, drug use, illness, suffering, and death to the specific issue of HIV/AIDS, providing a wide range of responses.

• HIV/AIDS has also been a subject of intense coverage in the realms of the popular media and of academic theory.

Coverage in the Encyclopedia:
The coverage of culture and society is fairly straightforward: all of the major artistic disciplines, forms of media and entertainment, and world religions have their own entries. Entries are also provided on groups associated with the arts and entertainment who have been heavily impacted. This section also includes several entries on academic/theoretical approaches to the study of the epidemic.

Entries on Arts, Entertainment, and Media

Artists and Entertainers
  Arts Community
  Dance and Performance Art
  Film
  Internet
  Journalism, Print
  Journalism, Television
  Literature
  Media Activism
  Music
  Periodicals
The Plague of Our Time: Societal Responses to AIDS

*Perspectives on the AIDS Epidemic: Culture and Society*

Nearly every major infectious disease has created not one but two epidemics: the illness itself and society’s reaction to it. Following initial denial there is hysteria and a search for a scapegoat. The fear of infection and the ignorance of its cause have often led to uncaring and even barbaric practices.

The Black Death of the Middle Ages killed more than 500 people per day at its peak. The central concern of many at that time was not to provide care or devise a cure, but rather to determine how deep to dig the graves in order to prevent further spread of the disease. Historically, lepers were cast from society and isolated; they were prohibited from touching their own children. In the 1830s, cholera was considered the punishment for people unwilling to change their lives, such as the poor and those thought to be immoral. In the early 20th century, polio in America was believed to be caused by Italian immigrants, and the influenza pandemic of 1918–1919 was blamed by some on the Irish.

It took centuries to understand how the plague was spread, decades to identify its cause and develop a cure. Just over 15 years ago, we first identified what has now become the epidemic of AIDS, and in that short time we have gained knowledge of the
causative agent, understanding of the manner of transmission, and reliable tests for infection. Fortunately, pioneering research has yielded many treatment options. Yet, even with all of our scientific technology, and despite the high level of education in the developed world, we have not advanced very far in our social responses to medical crises. At various stages of the AIDS epidemic, we also have engaged in denial, hysteria, and the search for a scapegoat.

Early on, it was difficult to capture the attention of either the public at large or political leaders, because AIDS seemed like “someone else’s disease.” At the highest level of the U.S. government, there was remarkable inaction by the administrations of Presidents Ronald Reagan and George Bush, demonstrating a disdain for those infected and an apathy toward their plight. At the same time, the educational needs of the public were largely ignored. This climate gave rise to frightening theories of genocide and government-sponsored germ warfare. There was a call for the control of AIDS chiefly by focusing on its most prominent victims. And it was conveniently believed by some that changes in personal behavior were unnecessary to curb the spread of AIDS; certainly heterosexuals need not worry about this disease of gay men. Gay communities were outraged that the disease was not regarded like any other public health crisis affecting society.

The anxiety first felt in the gay and hemophiliac populations later spread to the general public when it was disclosed that AIDS had affected celebrities with whom they more closely identified. There was also a growing awareness that AIDS was a disease of unknown origin with a prolonged incubation period, allowing apparently healthy people to unknowingly transmit the infection. There were few drugs that seemed even partially effective and no cure or vaccine. The illness appeared to be universally fatal. In addition, some politicians fueled this growing anxiety with calls for mandatory testing in order to isolate those infected. The evident connection with sexuality added a level of discomfort to the fear.

The scapegoat for this disease was quickly identified by some religious leaders who proclaimed AIDS as God’s retribution for the sinful acts of homosexuals. A distinction was made concerning those who were “innocently” infected and those who were not. On an international level, African countries felt accused by the western nations as the source of HIV. This unfortunately led to a blanket denial by some African countries that AIDS even existed within their borders, leading to a tragic delay of several years in responding to this rapidly growing menace.

From health care workers sliding trays of food into the doorways of AIDS patients to Washington, D.C., police officers wearing elbow-length rubber gloves when dealing with activists at the Third International AIDS Conference, stories of irrational behavior proliferated, even in the face of firmly established knowledge about transmission. As recently as 1995, U.S. Secret Service agents at the White House felt the need to wear gloves while doing a security check of a group of gay and lesbian visitors invited by President Bill Clinton.

Although calls for the isolation of patients never resulted in a national policy in the United States, many people living with HIV and AIDS have been shunned by their own families, co-workers and acquaintances, and even by some health professionals. One of the most egregious examples of this shunning was illustrated in a newspaper photograph of an infected baby’s crib in a hospital with a sign that read, “Do not touch!” Young
heroes with AIDS were living symbols of all those who had suffered not only the effects of HIV, but the vicious rejection by their communities. Clearly, these responses are not very different from those of ancient times.

Yet despite the bigotry, denial, ignorance, and apathy, AIDS became a catalyst in the communities hardest hit—rallying people to fight both the disease and the societal ills that intensified their struggle. A number of people found an inner strength that helped them to care for those infected with HIV and to create an atmosphere of acceptance and compassion. Some became activists to create change in governmental policies and society’s attitudes. A sense of pride flourished within the lesbian and gay community as a result of the outstanding work of grassroots organizations and the hundreds of thousands of hours of volunteer service by individuals across the United States. This dedication (in the face of the government’s response) led to a sense of “ownership” of the disease.

Over the past decade and a half, the epidemic, those infected, their caregivers, and the institutions have changed, reflecting the diversity of America at large. The disease is moving from an acute care inpatient problem to a chronic outpatient disease. Service groups have become multimillion-dollar organizations, requiring individuals trained in finance, development, and general administration. AIDS organizations number in the thousands.

As we move into the twenty-first century, we cannot allow ourselves to slide into apathy and complacency, taking for granted these monumental gains. Poverty, racism, homophobia, and the lack of quality education and health care will continue to threaten our ability to deal effectively with AIDS, as well as all future epidemics. We must seize this opportunity to reassess our humanity and improve the total health of our society.

MERVYN SILVERMAN

The Global Epidemic

Synopsis:

• While HIV/AIDS can be found throughout the world, the epidemic has established two broadly different patterns: one in the developed world and one in the developing world.

• In the countries of the developed world (which are characterized by advanced industrial economies and democratic governments), AIDS first emerged primarily among gay men, injecting drug users, and recipients of blood transfusions. Particularly in North America and western Europe, gay men and injecting drug users have remained heavily impacted, but the epidemic has shifted steadily toward impoverished communities, often composed of racial/ethnic minorities.

• In the countries of the developing world (which are characterized by agrarian or partially industrialized economies and often unstable or repressive governments), AIDS has been transmitted mostly through heterosexual intercourse in the general population, although certain populations such as prostitutes and migrants are at particular risk. Sub-Saharan Africa was the earliest and most heavily impacted region of the developing world, but the epidemic is spreading rapidly throughout Asia and Latin America as well.
Advances in treatment of HIV/AIDS have been limited largely to the developed world, remaining out of the financial reach of most developing countries. The major routes of assistance from the developed to the developing world have been a variety of international organizations that have attempted to track and respond to the global profile of the epidemic.

Coverage in the *Encyclopedia*:
The global epidemic is reflected in the *Encyclopedia* by entries on the various world regions. In many cases, the entries in this section serve as mirrors of the *Encyclopedia* as a whole, pointing out distinctive features in such other domains as government and activism, policy and law, culture and society, and impacted populations.

For the most part, space constraints have generally made it impossible to cover countries individually. Thus, in this volume, the countries of the world have been divided into regions that share common geopolitical and epidemiological characteristics. In general, countries that were assigned to the same region share many common characteristics that make possible the discussion of broader trends. This is particularly true for the regions of Europe and the Americas. The divisions used here do not necessarily correspond to other classificatory systems, such as those used by the World Health Organization or other international agencies.

Much of this volume focuses on the United States, and major subregions of the United States are discussed in specific entries. Most countries of the world are also covered, although some extremely small countries and those that have reported few or no AIDS cases have in some cases been excluded. Dimensions of the international response to HIV/AIDS are also covered in other essays.

The more than 200 countries, states, or territories covered by name in *Encyclopedia* entries are listed under the headings following. Many additional provinces, cities, and regions are also discussed in these and other entries. If a particular country was known by more than one name or if countries merged or divided during the period covered by the entry, the change is noted in parentheses.

Entries on the Americas

**Canada**

Caribbean Region Including the Bahamas, Barbados, Bermuda, British Virgin Islands, Cuba, Dominican Republic, Guadalupe, Grenada, Haiti, Jamaica, Martinique, Netherlands Antilles, Puerto Rico, Saint Kitts and Nevis, Saint Lucia, Saint Vincent and the Grenadines, Trinidad and Tobago, Turks and Caicos Islands, U.S. Virgin Islands

Mexico and Central America Including Belize, Costa Rica, El Salvador, Guatemala, Honduras, Mexico, Panama

South America Including Argentina, Bolivia, Brazil, Colombia, Chile, French Guiana, Guyana, Paraguay, Peru, Suriname, Uruguay, Venezuela

United States—Middle Atlantic Region Including Delaware, Maryland, New Jersey, New York, Pennsylvania, Washington, D.C.

United States—The Midwest Including Illinois, Indiana, Iowa, Kansas, Michigan, Minnesota, Missouri, Nebraska, North Dakota, Ohio, South Dakota, Wisconsin

United States—Mountain Region Including Colorado, Idaho, Montana, Nevada, Utah, Wyoming
United States—The South Including Alabama, Arkansas, Florida, Georgia, Kentucky, Louisiana, Mississippi, North Carolina, South Carolina, Tennessee, Virginia, West Virginia
United States—The Southwest Including Arizona, New Mexico, Oklahoma, Texas
United States—Western Pacific Region Including Alaska, California, Hawaii, Oregon, Washington, U.S. Pacific territories (American Samoa, Guam, Northern Mariana Islands), and associated nations (Marshall Islands, Micronesia, Palau)

Entries on Europe
Europe, Eastern Including Albania, Bulgaria, Czechoslovakia and its successor states (the Czech Republic and Slovakia), Hungary, Poland, Romania, Slovakia, Yugoslavia and its successor states (Bosnia and Herzegovina, Croatia, Macedonia, Slovenia)
Europe, Northern Including Austria, Belgium, Denmark, Finland, Germany (including the former East Germany), Iceland, Luxembourg, The Netherlands, Norway, Sweden, Switzerland
Europe, Southern Including Cyprus, France, Greece, Italy, Malta, Portugal, Spain
Russia and the Former Soviet Union Including The Soviet Union and its successor states (Armenia, Azerbaijan, Belarus, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Moldova, Russia, Tajikistan, Turkmenistan, Ukraine, Uzbekistan)
United Kingdom and Republic of Ireland

Entries on Asia and the Pacific
Asia, East Including China, Hong Kong, Japan, Mongolia, North Korea, South Korea, Taiwan
Asia, South Including Bangladesh, Bhutan, India, Myanmar (formerly Burma), Nepal Pakistan, Sri Lanka
Asia, Southeast Including Cambodia, Laos, Indonesia, Malaysia, Papua New Guinea, Philippines, Singapore, Thailand, Vietnam
Australia and New Zealand

Entries on Africa
Africa, East-Central Including Burundi, Central African Republic, Congo (formerly Zaire), Congo Republic, Equatorial Guinea, Ethiopia (including Eritrea), Gabon, Kenya, Rwanda, Tanzania, Uganda
Africa, Southern Including Angola, Botswana, Lesotho, Madagascar, Malawi, Mozambique, Namibia, South Africa, Swaziland, Zambia, Zimbabwe
Africa, West Including Benin, Burkina Faso, Cameroon, Cape Verde, Cote d’Ivoire, Gambia, Ghana, Guinea, Guinea Bissau, Liberia, Mali, Mauritania, Niger, Nigeria, Senegal, Sierra Leone, Togo
Middle East and North Africa Including Afghanistan, Algeria, Bahrain, Chad, Djibouti, Egypt, Iran, Iraq, Israel, Jordan, Kuwait, Lebanon, Libya, Morocco, Oman, Palestinian peoples (Gaza and West Bank), Qatar, Saudi Arabia, Somalia, Sudan, Syria, Turkey, Tunisia, United Arab Emirates, Yemen (includes North and South Yemen)
Entries on the International Response
Developed and Developing Worlds
International Organizations
National AIDS Programs

Parallel Epidemics: AIDS in the Developed and Developing Worlds

Perspectives on the AIDS Epidemic: The Global Epidemic

Although HIV, and thus the AIDS epidemic, can be found throughout the world, broadly different epidemiological patterns have emerged in the developed world as opposed to the developing world. These patterns can be discussed only in the most general terms and vary considerably from country to country and among subpopulations within countries. However, these patterns can be used to draw useful distinctions between the challenges posed by HIV/AIDS to the developed and developing worlds.

The term developed world refers to the comparatively wealthy countries and regions of the world whose economies are characterized by advanced industrial capitalism and whose political systems are generally representative democracies. The developed world is usually defined as comprising the United States, Canada, the countries of western Europe, Japan, and Australia and New Zealand, although parts of eastern and central Europe, East Asia, and Latin America are also sometimes included. Even though there are variations from country to country, the progression and profile of the HIV/AIDS epidemic in the developed world has had certain similar features.

The AIDS epidemic in the developed world was first detected clinically when a group of gay men from San Francisco were diagnosed with curious failures of the immune system and with swollen lymph nodes. Researchers determined that the virus was transmitted in three ways: by sexual intercourse, often between men; by exposure to contaminated blood or blood products, including by blood transfusions and the sharing of needles during injecting drug use; and from mother to infant before or at time of delivery or through subsequent breast-feeding. At least three main factors contributed to the early spread of HIV in the developed world: the “sexual revolution” of the 1960s and 1970s, an increase in drug use, and the advancement of blood product and transfusion technology.

Sexual liberation had come to Europe and North America in the late 1960s, and with it came gay liberation. Increased casual sex with multiple partners and with partners from other geographic areas and social settings helped foster the spread of HIV. Because the first clinical cases were observed in homosexual males, AIDS was initially thought throughout the developed world to be a “gay disease.” The second major route of transmission, which had great impact on the global spread of the disease, was transmission via contaminated blood and blood products. Evidence of contamination of the blood supply by what would later be identified as HIV first appeared in the United
States and in parts of Europe in 1982, when people with the blood disorder hemophilia began to manifest symptoms. The third major route of HIV transmission, “vertical” transmission from pregnant, infected women to their unborn children, first occurred mostly among injecting drug users in North America and Europe.

The epidemic in the developing world began in sub-Saharan Africa, with HIV transmission most intense in Uganda, Malawi, the Central African Republic, Kenya, Tanzania, Burundi, Rwanda, and Zambia, some of the poorest countries of the world. One of the earliest recognized manifestations of the epidemic was dramatic weight loss in certain individuals, called “slim disease” in parts of Africa and later correlated with AIDS-related wasting syndrome. Despite early description of the disease, major efforts to stem infection were not mounted internationally until 1987. In contrast to the pattern of sexual transmission in the developed world, it has been heterosexual rather than homosexual sexual behavior that has been responsible for most HIV transmission in the developing world. Thus the illness was generalized throughout societies early in the epidemic. Injecting drug users, recipients of blood transfusions, children born to HIV-positive mothers, prostitutes, refugees, and migrant workers have been heavily impacted. Although the epidemic in sub-Saharan Africa has remained the paradigm of HIV/AIDS in the developing world, later epidemics also emerged in the Caribbean, Latin America, India, and Southeast Asia, particularly Thailand.

Overall, the AIDS epidemic in the developing world has been characterized by extensive HIV transmission prior to the era of prevention; resource constraints, which have hampered education and prevention in spite of unprecedented levels of international aid to affected areas; and continued, preventable transmission despite lessons learned. Key programmatic decisions made by the international aid community included a de-emphasis on individual counseling and testing and on laboratory screening for HIV for these resource-poor settings. Some feel these decisions hampered prevention efforts. Because of these shortfalls, some of the poorest areas of the world are the most heavily affected. The costs in terms of human life and productivity in sub-Saharan Africa are overwhelming, as are projected costs for the epidemics in Latin America and Asia.

Recognizing that the epidemics in the developing and developed worlds are interconnected, there has been a significant international response to the epidemic. Part of this has come in the form of bilateral assistance between individual developed countries and specific developing countries. However, much of the collaboration between developed and developing countries has occurred through multilateral international agencies such as the World Health Organization, the United Nations Development Programme, and the Joint United Nations Programme on HIV/AIDS.

ANN MARIE KIMBALL
Abstinence

Abstinence refers to the practice of refraining from particular behaviors, typically those construed as being negative for or injurious to the person who performs them. In the context of HIV/AIDS, abstinence generally refers to the avoidance of HIV risk behaviors, including injecting drug use or certain sexual activities such as oral sex, vaginal intercourse, and anal intercourse.

In absolute terms, complete abstinence from risk behaviors is the single most effective manner in which to avoid any potential danger of HIV transmission through sex or injecting drug use. This approach to managing risk behavior, referred to as “harm elimination,” is reflected in programs that urge people, particularly adolescents, to “just say no” to all drug use as well as any pre- or extramarital sexual activity.

Harm-elimination approaches to drug use are typically enforced by prohibitionist laws that criminalize not only the use of illegal drugs but also the possession and distribution of needles and syringes. As regards sexual risk behavior, proponents of harm elimination typically endorse abstinence-only educational curricula, resist the distribution of condoms and contraceptives in schools, oppose teaching about homosexuality, and reject sex education in general and safer-sex education in particular. This approach is strongly advocated by religious conservatives, for whom drug use and sex outside heterosexual marriage are viewed not only as public health concerns but also as moral transgressions.

Complete abstinence from risk behaviors may be an attainable goal for some people, but many others may not be able to control their actions while under such powerful influences as sexual attraction and drug dependence or when they are under emotional stress or psychological pressure from others. Further, some who might be capable of controlling their actions may believe that certain risks are inevitable and that quality of life is dramatically compromised by the elimination of all risk. Such individuals may be helped by approaches that emphasize “harm reduction” over harm elimination.

The harm-reduction approach would argue that prevention of the sexual transmission of HIV need not involve abstinence from all sex, but rather only from certain unprotected sexual behaviors. Indeed, this is the fundamental message behind the concept of safer sex. From this perspective, sexual contact of various sorts can be continued as long as potentially infectious bodily fluids are not exchanged. Such a goal could be achieved by abstaining from all penetrative sex while continuing external sexual contact such as mutual masturbation and frottage (non-penetrative rubbing). Another, somewhat riskier alternative to total abstinence is the correct and consistent use of latex condoms during penetrative sex, particularly vaginal and anal intercourse.
In the case of injecting drug use, harm-reduction models usually begin with the reality of a given status quo: that a substantial number of people do, in fact, inject drugs and are likely to continue doing so for the foreseeable future. Although treatment programs designed to end drug dependence are often part of harm-reduction approaches, the greater emphasis is on dealing with the current practices of injecting drug users. The prototypical harm-reduction strategy has been the distribution of clean needles, usually in exchange for used needles. The distribution of bleach kits and information about how to clean used needles would be a distant second choice from the harm-reduction perspective, a strategy to be followed mainly when needle distribution is impossible.

Proponents of abstinence-based programs argue that, in the long run, harm-reduction programs simply serve to deepen fundamental underlying social problems such as drug use and sexual activity outside heterosexual marriage. They argue that making condoms readily available in schools or decriminalizing needle possession is tantamount to legitimating and even condoning such activity. Thus, they contend that non-abstinence-based programs in schools send mixed messages to youth and, in the end, lead more youth to have sex or to experiment with drugs than would be the case with abstinence-only programs. Proponents of abstinence also argue that the distribution of condoms and clean needles in prisons would be a tacit acknowledgment of the prevalence of prohibited activities such as sex and drug use among inmates. Opponents of harm-reduction approaches make pragmatic arguments, such as that many people are unable to control their sexual behavior once in a state of arousal and thus may engage in risky behaviors anyway. They also point out that condoms can and do sometimes rupture, slip off, and leak and thus are not foolproof.

The many ethical and policy debates regarding the question of abstinence have been stormy and sometimes characterized as part of a larger “culture war” being fought between groups with ideologically irreconcilable positions. Advocates of abstinence tend to believe that social leniency engendered the HIV/AIDS epidemic and that it can only be resolved by a return to stricter standards of behavior. Those who view abstinence as only one possible approach of many to HIV prevention tend to focus instead on the rights of individuals to make autonomous decisions.

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Related Entries: Adolescents; Educational Policy; Harm Reduction; Injecting Drug Use; Injecting Drug Users; Interventions; Monogamy; Needle-Exchange Programs; Safer Sex; Safer-Sex Education

Key Words: abstinence, celibacy, harm elimination, harm reduction, monogamy, sex education

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