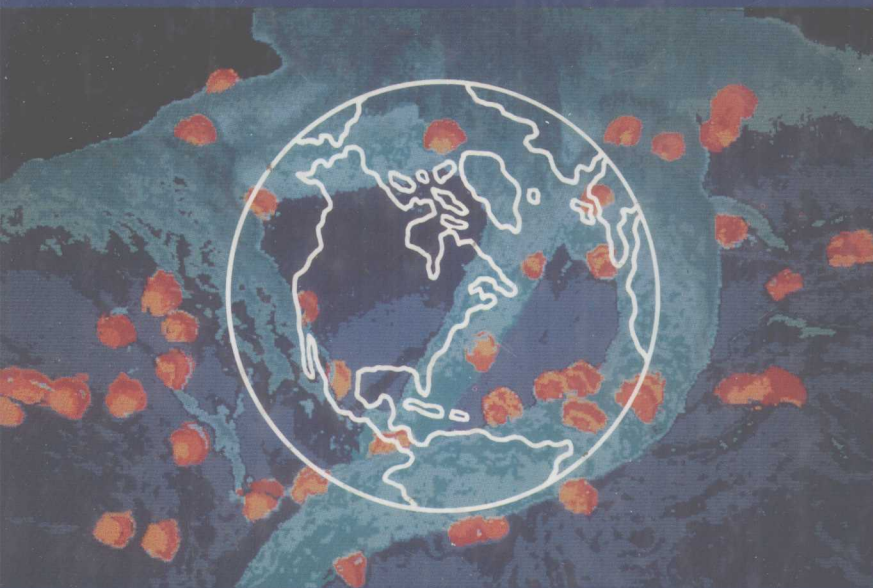


ACQUIRED IMMUNE DEFICIENCY SYNDROME



Biological,
Medical,
Social,
and Legal
Issues

GERALD J. STINE

ACQUIRED IMMUNE DEFICIENCY SYNDROME

*Biological, Medical, Social,
and Legal Issues*

GERALD J. STINE

University of North Florida, Jacksonville



PRENTICE HALL, Englewood Cliffs, New Jersey 07632

Library of Congress Cataloging-in-Publication Data

Stine, Gerald James.

Acquired immune deficiency syndrome: biological, medical, social,
and legal issues/Gerald J. Stine.

p. cm.

Includes bibliographical references and index.

ISBN 0-13-019811-0

1. AIDS (Disease) I. Title

[DNLM: 1. Acquired Immunodeficiency Syndrome. 2. AIDS
Serodiagnosis. 3. Confidentiality. 4. Counseling. 5. Health
Expenditures. 6. Knowledge, Attitudes, Practice. 7. Public Policy.
WD 308 S859a]

RC607.A26S75 1993

362.1'969792—dc20

DNLM/DLC

for Library of Congress

92-19795

CIP

Editorial/production supervision

and interior design: *Joanne E. Jimenez*

Acquisitions editor: *David Kendric Brake*

Cover design: *Lundgren Graphics, Ltd.*

Line illustrations: *Teresa M. St. John, University of North Florida*

Prepress buyer: *Paula Massenaro*

Manufacturing buyer: *Lori Bulwin*



© 1993 by Prentice-Hall, Inc.

A Simon & Schuster Company

Englewood Cliffs, New Jersey 07632

All rights reserved. No part of this book may be
reproduced, in any form or by any means,
without permission in writing from the publisher.

Printed in the United States of America

10 9 8 7 6 5 4 3 2 1

ISBN 0-13-019811-0

PRENTICE-HALL INTERNATIONAL (UK) LIMITED, LONDON

PRENTICE-HALL OF AUSTRALIA PTY. LIMITED, SYDNEY

PRENTICE-HALL CANADA INC., TORONTO

PRENTICE-HALL HISPANOAMERICANA, S.A., MEXICO

PRENTICE-HALL OF INDIA PRIVATE LIMITED, NEW DELHI

PRENTICE-HALL OF JAPAN, INC., TOKYO

SIMON & SCHUSTER ASIA PTE. LTD., SINGAPORE

EDITORA PRENTICE-HALL DO BRASIL, LTDA., RIO DE JANEIRO

*This book is dedicated to those who have died of AIDS,
those who have HIV disease,
and to those who must prevent the spread of this plague—
EVERYONE, EVERYWHERE.*

Preface

Acquired Immune Deficiency Syndrome: Biological, Medical, Social, and Legal Issues is a balanced review of the important aspects of human immunodeficiency virus (HIV) infection and Acquired Immune Deficiency Syndrome (AIDS). It is intended for use in college level courses on AIDS, in medical and nursing schools, in colleges of allied health sciences, in psychology department courses on human sexuality and human behavior, in courses on sexually transmitted diseases, in summer teachers' programs, in the training of AIDS counselors, in state mandated AIDS education courses for health care workers and for physicians who need a ready source of information on HIV infection, HIV disease and the expression of AIDS. This text is suitable in those cases where information and education about the various aspects of HIV infection, disease and AIDS is either wanted or required.

As the second decade of the AIDS epidemic begins, a review of what has been learned and what must still be learned to bring HIV infection and AIDS under control is valuable information to most, if not all.

This text offers answers to questions many people have about the AIDS virus and how their immune systems are affected by it. Covered herein are the activity of the immune system with respect to HIV disease, where the virus might have come from, how it is transmitted, who is most likely to become infected, viral prevalence (geographical distribution of the number of people infected and those expressing HIV disease and AIDS), possible means of preventing infection, the signs and symptoms of HIV disease and AIDS, a definition of AIDS, the opportunistic infections most often associated with AIDS, FDA approved and non-approved

drugs and their effectiveness, the potential for a vaccine to the AIDS virus, the tests available to detect HIV infection, the accuracy of these tests, their cost, availability and confidentiality. The last three chapters present the social, economic and legal issues associated with HIV disease and AIDS. These chapters deal with fear, the economic cost, problems of insurability for those who are considered to be in a high-risk group for HIV infection, social reaction of the uninfected toward the HIV-infected, acts of discrimination and the laws in place to protect people with HIV/AIDS.

The majority of references herein are dated between 1987 and 1992. Every state in the U.S. has reported HIV-infected people and people diagnosed with AIDS. The World Health Organization (WHO) reports that of 178 nations reporting to it, 157 have reported diagnosed cases of AIDS. The virus is truly pandemic and now threatens most of the human population. Yet it is a preventable disorder and the steps to prevention are presented in Chapter 7.

During the 11 years since it was defined as a new disease, more manpower and money has been poured into HIV/AIDS research than into any other disease in history. Information on the AIDS virus has accumulated at an unprecedented pace. Since the discovery of the AIDS virus in 1982–83, scientists have learned much about how it functions and how it affects the immune system. More has been learned about the AIDS virus in the first six years after its discovery than had been learned about the polio virus in the first 40 years of the polio epidemic. During the first six years of AIDS research, the virus' genetic material had been cloned, its structure ascertained and individual viral genes identified. In fact, so many billions of dollars have been spent on HIV/AIDS that there are many who now believe that HIV/AIDS research has taken away much needed resources from other diseases that kill many times more people per year than does AIDS. It would appear that a new balance for funding must be found in the future.

Organization of the Text

The text consists of 14 chapters. Chapter 1 presents information on human mechanisms of defense against HIV infection. The human immune system is discussed with particular emphasis on how it is believed that the AIDS virus interacts with and affects the immune system, ultimately leading to a variety of opportunistic infections, disease and a diagnosis of AIDS. Chapter 2 discusses the cause of AIDS, naming the virus, its origins, genetics and immunology. Chapter 3 discusses opportunistic infections. Chapter 4 presents the clinical indicators of HIV disease and progression toward AIDS. Chapter 5 discusses possible therapies. Chapters 6, 7, 8, 9, 10, 11, 12, 13 and 14 cover how the AIDS virus is most efficiently transmitted (6), prevention of HIV infection (7), the prevalence of HIV infection and AIDS in the United States (8) and in other countries (9), antibody testing for HIV (10), pre and post test counseling (11), social implications of being HIV-infected (12), the economic issues of this new disease (13), and the relationships of HIV/AIDS to handicap and laws to prevent discrimination (14). There is also a glossary of terms.

Each chapter contains chapter concepts, a summary, review questions and references. Each chapter also contains definitions for new terms as they are introduced, illustrations, photographs and tables. All 14 chapters contain boxed information. Some of the chapters contain points of view, points of information, cases in point and pro and con discussions. These illustrate and highlight important information about HIV infection, disease and AIDS. At certain places in the text, discussion statements are provided. Instructors may wish to entertain class discussions in these areas.

As science educators, it is our job to turn out students who have been exposed to the new concepts in biology that are shaping humanity's future. To do that, we must expose them to new vocabulary, new methodologies and new ideas. It is my hope that this text will help in this endeavor.

In Appreciation

The help of the following organizations or people is most deeply appreciated:

The Centers For Disease Control (CDC), Atlanta, Georgia, for use of slides and literature produced in their *National Surveillance Report* and the *Morbidity and Mortality Weekly Report*; Mara Lavitt and *The New Haven Register* for information on William Bluette; Robert N. Kermescher, chief of Education and Training at the CDC for his valuable references on AIDS information; E.E. Buff, Biological Administrator, and Barry Bennett, head of Retroviral Testing Services for their permission and guidance on photographing HIV testing procedures at the Florida Health and Rehabilitation Office of Laboratories Services, Jacksonville, Fla.; to Karen Rodriguez and Roni Sanlo, AIDS Unit, Public Health Service, Jacksonville, Fla.; Russ Havlak of the Infectious Disease Unit, CDC, Atlanta, Ga.; personnel of the National Institute for Allergy and Infectious Diseases, the National Center for Health Statistics, Brookwood Center for Children with AIDS in NY, the George Washington AIDS Policy Center in Washington, D.C., the National Institutes for Health, Hoffman-LaRoche Co., Abbott Laboratories, the Pharmaceutical Mfg. Association, the National Cancer Institute, Pan American Health Organization and the Office of Technological Assessment; Teresa M. St. John, University of North Florida for illustrations; the individuals who have contributed photographs; the text reviewers whose work has been greatly appreciated; Joan Trowbridge for preliminary editing;

Larry Monette, who spent countless hours on weekends word processing this manuscript; Guy Selander, M.D. and Jack Giddings, M.D., who, over the years, have shared their medical journals with me; James Alderman, Eileen Brady, Mary Davis, Signe Evans, Paul Mosley, Ricky Moyer, Sarah Philips, Peggy Pruett and Barbara Tuck—reference/research librarians at the University of North Florida; and to my special family—wife Delores and children Sherri and Garrett, who helped with proof-reading and demonstrated a great deal of patience and understanding and gave up family weekends so the text could be completed on time.

This book has benefited from the critical evaluation of the following reviewers:

- ◆ Dr. Kathaleen C. Bloom, University of North Florida
- ◆ Dr. Paul R. Elliott, Florida State University
- ◆ Dr. Robert Fulton, University of Minnesota
- ◆ Dr. Robert M. Kitchin, University of Wyoming
- ◆ Dr. Richard J. McCloskey, Boise State University
- ◆ Dr. Wayne B. Merkley, Drake University
- ◆ Dr. Linda L. Williford Pifer, University of Tennessee
- ◆ Dr. Bernard P. Sagik, Drexel University
- ◆ Professor James D. Slack, Cleveland State University
- ◆ Dr. Carl F. Ware, University of California, Riverside
- ◆ Dr. Charles Wood, University of Kansas

Gerald J. Stine, Ph.D.

Introduction

HISTORY OF GLOBAL EPIDEMICS

The history of epidemics dates as far back as 430 B.C. Epidemics are not new to humankind, but the fear they impose on each generation is.

Major recorded pandemics (global) and epidemics (regional) that have devastated large populations are described in Table I-1.

The acquired immune deficiency syndrome (AIDS) pandemic is certainly one of the defining events of our time. There are stories to be told from it, stories of the people infected and affected by it—the well, the ill, the dying and the survivors. And there are the stories of scientific discovery, of the human immunodeficiency virus (HIV) and viral mechanisms and of genetic mysteries being understood. And then there

are stories of scientific politics, claims and counterclaims, and the manipulating that goes on in the stratosphere of high-level science.

“A third of the world died,” wrote Jean Froissart at the end of the 14th century, when medieval medicine had little to offer against the Black Death. Now, at the end of the 20th century, we see modern science registering its progress about a plague of our own time.

AIDS is the most dramatic, pervasive and tragic pandemic in recent history. It consists of two parts: one medical, the other social. HIV/AIDS infection has provoked a reassessment of society's approaches to public health strategy, health care resource allocation, medical research and sexual behavior. Fear and discrimination have affected virtually every aspect of our culture. Both the medical challenge and, in particular, the

TABLE I-1 Plagues in History

Disease	Dates	Place	Number Killed	Causative Organism	Time to Prevention/Cure (in years)
Measles	From 251 A.D.	Rome/World	millions	Paramyxovirus	1,712
Bubonic Plague	1347–1351	Europe/Asia/Africa	75,000,000	Pasteurella Pestis	580
Cholera	1826–1837	New Jersey	900,000	Vibrio Cholerae	75
	1849	United Kingdom	53,293		
	1947	Egypt	11,755		
Tuberculosis	1930–1949	United States	1,000,000	Mycobacterium Tuberculosis	85
	1954–1970		150,000		
Malaria	1847–1875	Africa/India	20,000,000 +	Plasmodia	100
Scarlet Fever	1861–1870	United Kingdom	972 per million people	Beta-Hemolytic Streptococci	45–55
Polio	1921–1970	North America	37,000	Polio Virus Types I, II, III	30–50
Typhus	1917–1921	Russia	2,500,000	Rickettsias	25
Influenza	1918–1919	U.S./Europe	21,640,000	Influenza Virus	57
Smallpox	Middle Ages	Europe	Hundreds of thousands	Smallpox Virus	2,390
	1926–1930	India	423,000		
Gonorrhea	from 590 BC				
	1921–1992	United States	57,477	Neisseria Gonorrhoeae	1,832
	from 160 AD				
Yellow Fever	1986–1988	Nigeria	10,000	Arbovirus	448
AIDS			Deaths Cases	Human Immunodeficiency Virus	Treatments but No Cure
	1981–6/30/92	United States	145,000 235,000		
	1981–6/30/92	World	>350,000 1,500,000		

social challenge will continue in the foreseeable future. Arthur Ashe, a world-class tennis player, so feared discrimination against himself and family that he lived with AIDS for three and a half years before he was forced to reveal he had AIDS (Figure I-1).

The fear of HIV infection, and the ignorance about its causes have created bizarre behavior and at times barbaric practices, strange rituals and the attempt to isolate those afflicted.

The Black Plague during its most destructive time was killing over 500 people a day. Instead of being concerned about providing care to the victims, people spent their time deciding how deep to dig the graves so that none of the horrid fumes would come up and infect others. It was determined that a grave should be six feet deep; and that is exactly how deep it is today. Plague victims were herded together into cathedrals to die or to pray for faith healing to save them. In 14th century Germany and Switzerland,

the Christians blamed the Jews for the outbreak of bubonic plague, believing that the Jews were poisoning the water—the very same water that the Jews were drinking. As a result, whole communities of Jews were slaughtered. In the 1930s, cholera was considered a punishment for people unwilling to change their lives—the poor and the immoral. In the early 20th century, polio in America was believed to be caused by Italian immigrants. And in the 1400s and 1500s, when syphilis was spreading across the world and killing thousands, the Italians called it the French disease. Of course, the French called it the Italian disease.

The worldwide flu epidemic of 1918 and 1919 caused between 20 and 50 million deaths in people between the ages of 20 and 40. In San Francisco, all citizens were required to wear masks. One form of therapy was ‘cabbage baths’. People did not jump into a tub with some cooked cabbage; they ate the cabbage and urinated into the tub.

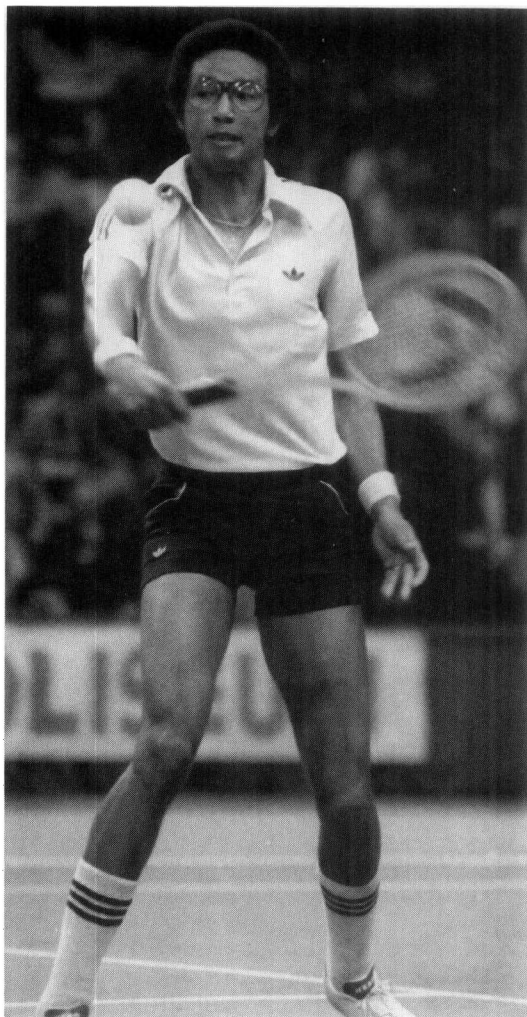


FIGURE I-1 Arthur Ashe—Winner of Two United States Tennis Championships. On April 8, 1992 Ashe announced that he had AIDS. He became infected with HIV from a blood transfusion during heart bypass surgery in 1983. Ashe was the United States Davis Cup Captain for five years and supported the NCAA Proposition 42 academic requirements for athletes. In 1975 he became the first black to win a Wimbledon mens title. Since learning that he had AIDS, Ashe completed his third book, *A Hard Road to Glory*, a three volume history of black athletes in the United States. (Photograph courtesy of API/Wide World Photos)

The flu victims then got into the tub. There may have been a positive side to the bath because once you got out, a distance was created between you and other people. In this way, the baths may have helped stop person-to-person transmission.

In 1937, 112,000 Americans contracted tuberculosis and 70,000 died. Parents and children quietly coped—the ill were served, not shunned.

DESCRIPTION OF AN AIDS PATIENT

Cecilia Worth is a registered nurse and author. In a recent edition of *The New York Times Magazine* she wrote:

Clustered near the bed, framed photos show a burly athlete who placed in the triathlon, a handsome man who grins disarmingly, an arm slung around his wife's shoulders. Now, transformed into a skin and bones caricature of himself, he is ruled by fatigue. After an interminable struggle to reach the bathroom, knees buckling, leg muscles barely able to hoist his feet forward over the floor, a heroic effort of will, he collapses back in bed, exhausted, motionless, glaring from huge, haunted eyes when I speak to him.

Only in his wife's presence is he calm, though no less armored. She is angry, too, and afraid of him. She cooks for him but will not touch him. His children, parents, brother visit often, struggle for words, and leave without embracing.

He rejects kindness in any form. To my cordial first greeting, he responds with silence, slamming shut his eyes. To suggestions of television, music, back rubs, his response is emphatic, curt: "No!"

Worth vividly describes some of the agony of this terrible disease. She also describes the mental and emotional strain that tears at family life.

There is a point at which sickness and dying cease to offer insights into the human condition and become instead an unbearable, unredeemable absurdity. This is most often how AIDS appears to those who know it.

An alarming feature of HIV infection is that you cannot look at someone and determine whether he or she is infected—a person can be infected and transmit the virus to others for years before becoming ill. Like other disease-causing organisms and viruses, HIV does not recognize age, race, religion, ethnic group or gender. The virus is very democratic.

AIDS—A RECENT CAUSE OF DEATH

AIDS is now one of the 10 leading causes of death among one to four-year-olds and among 15 to 24-year-olds in the United States. In New York, it is the leading cause of death among men and women 20 to 49 years old.

There is the expectation that parents will die before their children. Because of the HIV/AIDS epidemic, it is not working out that way for thousands of parents. They are watching their children die in the prime of life.

The facts on HIV infection, disease and AIDS presented in the following chapters, when understood, clearly place the responsibility for avoiding it on YOU. You must assess your lifestyle; if you choose not to be abstinent, you must know about your sexual partner and you must practice safer sex. Never think that you are immune to HIV infection.

FIRST REPORTS ON AIDS CASES IN THE UNITED STATES

On June 5, 1981, the first cases of the illness now known as acquired immunodeficiency syndrome (AIDS) were reported from Los Angeles in five young homosexual men diagnosed with *Pneumocystis carinii* pneumonia and other opportunistic infections.

Initially, AIDS appeared among homosexual males; most frequently those who had many sex partners. Further study of the gay population led to the conclusion that the agent responsible for AIDS was being transmitted through sexual activities.

In 1982, cases of AIDS were reported among hemophiliacs, people who had received blood transfusions and injection drug users. These reports all had one thing in common—an exchange of body fluids, in particular blood or semen, was involved. In January 1983, the first cases of AIDS in heterosexuals were documented. Two females, both sexual partners of IDUs, became AIDS patients. This was clear evidence that the infectious agent could be transmitted from male to female as well as from male to male. Later in 1983, cases of AIDS were reported in Central Africa, but with a different twist. All of the African AIDS cases were heterosexuals who did **not** use injection drugs. These data supported the earlier findings from the American homosexual population: AIDS was primarily a sexually transmitted disease. And the risk for contracting AIDS increased with the number of sex partners one had and the sexual behaviors of those partners. Thus early empirical observations on which kinds of social behavior placed one at greatest risk of acquiring AIDS were later supported by surveillance surveys, testing and analysis.

By mid-1992, state and territorial health departments had reported over 235,000 cases of AIDS and over 144,000 AIDS-related deaths to the Centers for Disease Control. AIDS is now a major cause of morbidity and mortality in children and young adults in the United States, ranking seventh among estimated years of potential life lost before age 65 in 1987 and 15th among leading causes of death in 1988. In 1981, 265 people were reported to have AIDS. Eleven years later, over 235,000 people were reported to have AIDS. The first 50,000 cases of AIDS were reported to the CDC from June 1981 to December 1987 (7 years); the second 50,000 were reported between January 1988 and July 1989 (17 months). The third 50,000 cases were reported between August 1989 and the end of October 1990 (13 months). The fourth 50,000 were reported between October 1990 and October 1991 (12 months). It took eight years to record the first 100,000 AIDS cases but just two years for the next 100,000.

Epidemiological data collected worldwide clearly indicate that the AIDS virus is transmitted during sexual activities that involve the exchange of HIV-infected semen or vaginal fluids, by receipt of HIV-infected blood or blood products and from HIV-infected mothers to their fetuses or to their newborns during breast feeding.

Although homosexual/bisexual men still account for most reported AIDS cases, IDUs, their sex partners and their children represent an increasing proportion of cases. Of AIDS cases reported before 1985, 63% were homosexual/bisexual men with no history of IDU, 18% were female or heterosexual male IDUs and 2% were the sex partners or children of IDUs. In contrast, of the AIDS cases reported in the first six months of 1992, 56% were homosexual/bisexual men with no history of injection drug use, 23% were female or heterosexual male IDUs and 4% were the sex partners or children of IDUs. The proportion of AIDS cases among women has also increased from 7% before 1985 to 12.5% in the first six months of 1992. Blacks and Hispanics continue to be disproportionately represented, particularly among IDUs with AIDS.

Accuracy— The 235,000 AIDS cases reported in the United States by mid-1992 represent the minimum number of people with AIDS. Because of underreporting of AIDS cases and manifestations of HIV infection that do not meet the CDC AIDS surveillance case definition, the number of people with AIDS is underestimated. Accuracy in diagnosing and reporting AIDS cases varies by geographic region and patient population; however, mortality studies suggest that 70 to 90% of HIV-related deaths are identified through national surveillance.

The number of AIDS cases is one indication of the larger pandemic of HIV infection. An estimated one to two million people are infected with HIV in the United States; recent seroprevalence studies suggest that the actual number is closer to the middle of this range. Probably only 20 to

30% of HIV-infected people know they are infected. This means that of the over one million HIV-infected people in the United States, about 700,000 to 800,000 do not know it!

A study of homosexual/bisexual men in San Francisco suggests that 54% of those infected will develop AIDS within 10 years and that up to 99% will eventually develop AIDS. Therefore, as new cases of HIV infection occur and people progress through HIV disease, the number of people with AIDS will continue to increase.

Health care— By the end of 1992, health care costs for people infected with the AIDS virus will run into five to 20 billions of dollars. The cumulative number of AIDS cases in that year is expected to reach about 300,000 with 200,000 deaths. The large number of newly HIV-infected and those progressing to AIDS each year has already placed a strain on the United States health care system and the situation promises to get worse. (See Chapter 13 for more on the cost of the AIDS Industry.)

Reportability— AIDS is reportable in all 50 states, the District of Columbia and United States territories. AIDS surveillance has been crucial in identifying people at risk for the disease and the modes of transmission. AIDS surveillance data together with HIV surveys are important components of public health programs directed toward controlling HIV infection, and assist in providing the most accurate picture of the HIV epidemic in the United States.

THE EDUCATIONAL COMMUNITY

Like most complex problems, the AIDS epidemic poses special problems for educators. One of the most disturbing is discrimination against HIV-infected children. Guidelines from the U.S. Surgeon General, federal and state health officials and the medical community have not calmed the fears of misinformed parents. Many stories have made headlines and television news

TABLE I-2 1988 Gallup Poll Results* on Age-Related HIV/AIDS School Education

	National Totals %	Public School Parents %	Non-Public School Parents %
The Gallup Poll asked those who favored having public schools develop an HIV education program (90% of all respondents) the following questions:			
At what age should students begin participating in an HIV education program?			
Under 5 years	6	5	11
5-9 years	40	43	42
10-12 years	40	39	32
13-15 years	10	11	13
16 years or older	1	1	1
Don't know	3	1	1
Should public schools teach what is called 'safer sex' for HIV prevention? (This was understood to mean teaching about the use of condoms.)			
Should	78	81	82
Should not	16	16	25
Don't know	6	3	3

* Source: 20th Annual Gallup Poll on the Public's Attitudes Toward the Public Schools

concerning children who have been barred from attending school. While the courts can order admission, they cannot assure acceptance. Persuasion must come through a better understanding of the disease. Parents can be reassured through reminders that HIV/AIDS is not transmitted by casual contact. Students must also be educated about HIV/AIDS. The following Gallup Poll results (Table I-2), although taken in 1988, are about what one would still find true in 1992.

GOVERNMENT TO RULE ON HIV-INFECTED FOREIGNERS

The National Commission on AIDS has urged the Bush administration to scrap its prohibition against HIV-infected foreigners. For the past three years, international visitors have been questioned by the Immigration and Naturalization Service, and those who admit to testing HIV-positive can be denied visas. An exemption for travelers attending international conferences or business meetings was added in 1990.

THE FIFTH INTERNATIONAL CONFERENCE ON AIDS

For the first time in five international AIDS conferences, Persons With AIDS (PWAs, now referred to as PLWAs, or Persons Living With AIDS) were given scheduled time to address their concerns. These conferences have grown in size to the point that scientists are questioning their usefulness. Some idea of what has transpired can be gained from a comparison of the first and fifth meetings:

THE FIRST INTERNATIONAL CONFERENCE ON AIDS, ATLANTA, 1985:

◆ Number of delegates	2,000
◆ Number of speakers	150
◆ Number of posters	250
◆ Number of AIDS cases	9,608
◆ Number of deaths	4,712

THE FIFTH INTERNATIONAL CONFERENCE ON AIDS, MONTREAL, 1989:

◆ Number of delegates	12,000
◆ Number of speakers	1,047

◆ Number of posters	3,596
◆ Number of abstracts published	5,909
◆ Number of AIDS cases	97,193
◆ Number of deaths	56,468

THE SEVENTH INTERNATIONAL CONFERENCE ON AIDS

The Seventh International Conference on AIDS took place from June 16 to June 21 in Florence, Italy. Nine thousand people were in attendance. The slogan for this conference was 'Science Challenging AIDS.' Perhaps it should have been the reverse: 'AIDS Challenging Science.' Few advances in HIV/AIDS therapy or vaccine development were presented. Perhaps the most notable event was the squabble about where the 1992 conference would be held. Organizers of the 1992 conference, which was scheduled for Boston, decided that because of the United States government's restriction on HIV-positive immigrants, it will be held in Amsterdam. The 1993 conference is scheduled for Berlin; the 1994 conference will be in Japan.

THE AIDS MEMORIAL QUILT

The purpose of the quilt is to educate. The 'AIDS Quilt' is made up of individual fabric panels, each the size of a grave, measuring three feet by six feet, stitched together. In October 1987, the AIDS quilt was first put on display on the mall in Washington, D.C. At that time it contained 1,920 panels and covered an area larger than two football fields. By early 1992, the quilt contained over 15,000 panels bearing over 21,000 names, required about 20 acres to lay out and weighed sixteen tons. There are about 33 miles of seams and 17 miles of canvas edging. There are panels from each of the 50 states. Each day new panels arrive from across the United States and 26 foreign countries to be added to the quilt (Figure I-2). For those left behind, the panels represent an expression of love and a sign of grief—a part of the healing process (Figure I-3).

Some names on the quilt you may recognize are: Michael Bennett, director/chooreographer; Mel Boozer, gay rights activist; Sonia Singleton, AIDS activist; Arthur Bresnan, Jr. and Colin Higgins, film makers;



FIGURE I-2 Photograph taken from the quilt in July of 1991.



FIGURE I-3 A photograph of a single panel of the quilt taken in July of 1991.

Roy Cohn, attorney; Perry Ellis, fashion designer; Dan Eicholtz, cartoonist; Wayland Flowers, comedian; Michel Foucault, philosopher; Philip-Dimitri Galas, playwright; Keith Haring, artist; Brad Davis, actor (Figure I-4); Rock Hudson, actor (Figure I-5); Liberace, performer (Figure I-6); Charles Ludlum, actor/director/playwright; Robert Mapplethorpe, photographer; Leonard Matlovich, gay rights activist; Stewart McKinney, U.S. Congressman, R-CT; Court Miller, actor; Ed Mock, choreographer; Klaus Nomi, performance artist; Max Robinson, ABC news anchor; Tom Cassidy, Cable News Network business anchorman; Jerry Smith, Washington Redskins football player; Willi Smith, fashion designer; Chris-

topher Stryker, actor; Stephen Stucker, actor; Sylvester, singer; Dan Turner, AIDS activist; Dr. Tom Waddell, Olympic athlete; Stephen Kolzak, casting director for *Cheers*; Ryan White, teenager; Rickey Wilson, guitarist with the B-52s; Freddie Mercury, rock singer of Queen; Dan Bradley, funded a legal agency for the poor; Esteban DeJesus, light-weight boxing champion; Belinda Mason, only member with AIDS on President Bush's National Commission on AIDS; Kimberly Bergalis, first case of HIV infection from a health care provider—her dentist; Rob McCall, winner of the Olympic bronze medal for ice skating/dancing; and Alan Menken, Oscar winner for Best Original Score and Best Song for the 1991 film, *Beauty and the Beast*.

Portions of the quilt are on tour in major cities. Donations made for viewing the quilt are being used to support local Names Project chapters and their staffs.

Each panel has its own story. The stories are told by those who make the panels for their lost friends, lovers, parents and children. These two excerpts come from the book *The Quilt: Stories from the Names Project* by Cindy Ruskin, Matt Herron and Deborah Zemkie.

"Ours was a unique relationship," writes Art Peterson from Atlanta, Georgia, who created this cloth memorial to his lover, 27-year-old Reggie Hightower. "We had lots of obstacles which we overcame to make our relationship grow: He was deaf, I was hearing; he was black, I was white. But we were both gay and proud. We agreed that these were the happiest times of our lives. We lived and shared a totally married life.

"I don't have many ideas on how he should be memorialized—perhaps a carving on the side of Stone Mountain here in Georgia. I feel it's a shame that I can't convey to others how great a life he lived. How do I fully express his life to those who never met him? The memories are so wonderful and yet they cause so much pain. Reggie's panel is composed of shirts that he wore—some his, some mine (Figure I-7—quilt panel A). They were hand-sewn (by me) with double thread for strength and durability. Please display it prominently.



FIGURE I-4 Brad Davis, Filmstar. Voted best actor by the Foreign Press Association's Golden Globes Awards (1979) for his work in "Midnight Express". The film was the story of an American imprisoned in Turkey. Brad became HIV-infected through drug use and died at age 41 in 1991. (Photograph courtesy of AP/Wide World Photos)

"The hand sign in the middle [of the panel] is sign language for 'I love you'."

Several years ago, Wayne Hadley's landlord told him that a man dying of AIDS was moving in next door. Hadley, a Cincinnati schoolteacher, doesn't remember if he ever saw this neighbor, but does know that he felt a deep need to memorialize him. "I'd sit on the couch and gaze out my bay window and wonder what he was doing," Hadley says. "I'd wonder if maybe he was sitting at his bay window thinking about his life and dying, and wonder if he was frightened. I needed to say something for him and for all of us that know the fear of uncertainty."

Wayne designed a yellow horizontal banner with a single figure in silhouette on one side, and a shadow running along the bottom (Figure I-7—quilt panel B). In purple lettering, he wrote, 'Our Brother Next Door.' "Once I decided to do it, the banner just kind of made itself," says Wayne. "While I was making it, I felt very private—it was a real personal thing."

For more information about the Names Project's AIDS Memorial Quilt, call (415) 863-5511.

For information about your state chapter, contact the Names Project coordinator at (201) 888-1790.

WORLD AIDS DAY

December 1, 1988 was acclaimed **World AIDS Day (WAD)**. World AIDS Day is a day set aside to pay tribute to those who have AIDS and to those who have died of AIDS. Its purpose is to increase our awareness of AIDS. The first WAD did not attract much attention outside the gay community. But in 1989, artists got together and held the first annual **Day Without Art** to coincide with World AIDS Day. For the second annual Day Without Art/World AIDS Day on December 1, 1990, at least 3,000 art orga-

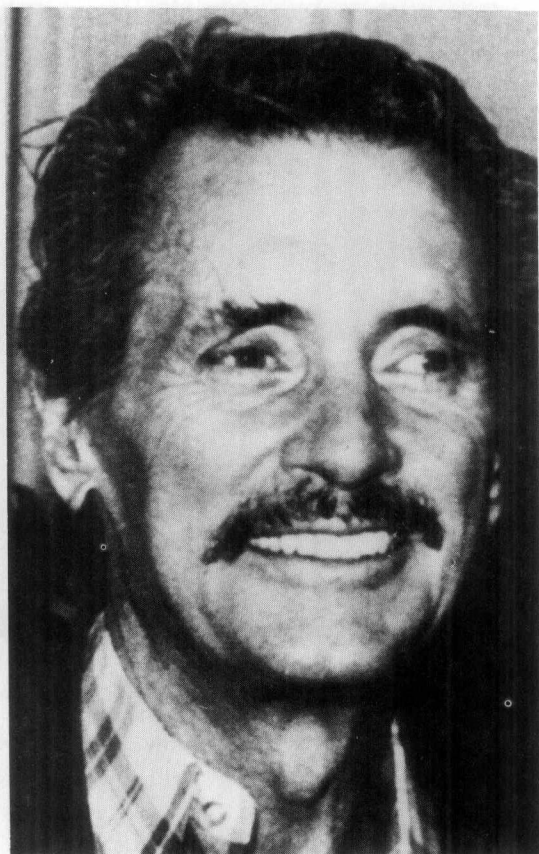
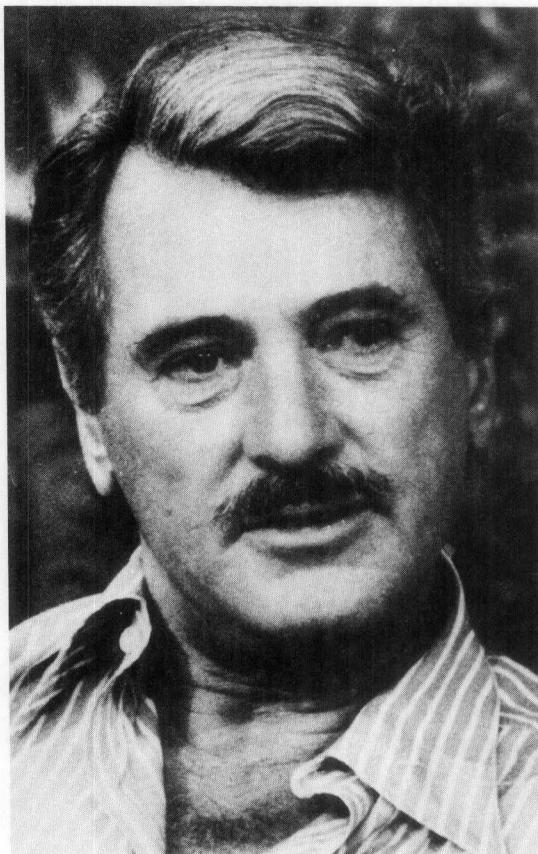


FIGURE I-5 Rock Hudson, Movie and Television Star. A Hollywood legend and undisclosed homosexual. He was the first major public figure to reveal he had AIDS. Hudson died in 1985 at age 59.
(Photograph courtesy of AP/Wide World Photos)

nizations in the United States were involved. They included the Smithsonian Institution as well as small American art galleries and art galleries in Canada, England, France and the Netherlands.

The second annual Day Without Art/World AIDS Day was commemorated by shrouded sculptures, darkened marquees and exhibits depicting the loss of life to HIV infection and AIDS. At 8 P.M. on December 1, 1990, the Manhattan and San Francisco skylines were dimmed for 15 minutes. On Broadway, the marquees were darkened for one minute and 23 cable TV stations as well as broadcasts in England, Canada and Aus-

tralia were interrupted with a one minute announcement about AIDS.

The third annual Day With Art/World AIDS Day was the largest AIDS event ever. The theme was 'sharing the challenge.' It was intended to underline the global nature of the pandemic and to foster awareness that only by pooling efforts, resources and imagination can hope prevail against the common threat. Many more people, businesses and industries became involved for the first time. For information on World AIDS Day 1992, write 108 Leonard Street, 13th Floor, New York, NY 10013 or call (212) 513-0303.