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# The Truth About ALL S The Truth About The Truth About

### Evolution of an Epidemic

**REVISED AND UPDATED** 

ANN GIUDICI FETTNER AND WILLIAM A.CHECK, Ph.D.

FOREWORD BY BIJAN SAFAI, M.D.

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### Evolution of an Epidemic

Revised and Updated Edition

Ann Giudici Fettner

AND
William A. Check, Ph.D.

Foreword by Bijan Safai, M.D.

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### First-Prize Winner in the American Medical Writers Association Book Awards Competition

"A compelling medical detective story . . . a readable nontechnical, and informed account of the history, research, treatment, and sociopolitical concerns surrounding AIDS."

-Choice

"Of all the 'non-medical' AIDS books to appear thus far, this volume will be the most readable and interesting for the general public and health professional alike. Fettner's writing style is engaging and direct. Her perspectives are well-informed: her insights are pointed and bold. . . . If you have never read an 'AIDS' book and want a very thorough overview, read this one. If you have read all the AIDS books, this one will complete your understanding."

-Dr. James Deramo, The New York Native

"An exemplary chronicle . . . the authors offer a factual and stunning detective story recording the discovery of the condition, the theories as to its etiology, and the unending search for a vaccine or cure."

-Booklist

"[A] splendid book, a perfect example of a balanced, intelligent look at a terrible scourge. . . ."

—Chattanooga Daily Times

For my children, their children, and the memory of Beatrice Ambasa of Marigoli —A.G.F.

For my wife and children —W.A.C.

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—Ann Giudici Fettner

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-William A. Check

### Foreword

For over four years, our society has been faced with a major epidemic. The Acquired Immune Deficiency Syndrome, or AIDS—named for the progressive loss of immune function in its victims—has sickened or killed thousands of people worldwide, and the mortality rate is virtually as high today as it was four years ago. In a world where the great advances in medical science and technology over the past few decades had made physicians confident that the infectious diseases of mankind were both curable and largely under control, AIDS is causing the kind of panic and suffering that we associate with a bygone age.

When the exquisitely complex mechanisms of the immune system are functioning normally, they identify, attack, and kill foreign pathogens. When this system fails, as it does in AIDS, the body is helpless against an awesome array of disease processes. The resulting breakdown in immunologic surveillance leads to a wide spectrum of clinical disorders, including the formerly rare cancer Kaposi's sarcoma and lifethreatening opportunistic infections. What causes this dys-

function is apparently a newly identified retroviral family. Even though suspicion falls heavily on the HTLV-III/LAV virus, some researchers question whether this agent alone causes AIDS. We still do not know whether the causative agent is new, recently transformed, or recently discovered.

The group most severely devastated has been male homosexuals. For these men, along with the horror of the disease itself, is the knowledge that their life-style is or could well become the cause of their death. Although the psychosocial impact of this fact has forced many homosexual men to reevaluate and change their social and sexual behavior, others find such modification difficult if not impossible. The observation that the disease can be transmitted through blood products has caused understandable panic in hemophiliacs and others whose lives depend on transfusions.

The tragedy of AIDS extends beyond its original victims. The epidemic has aroused legitimate concern for their own safety among health-care personnel who work daily with the blood and secretions of AIDS patients. The frustration of clinicians, who have to care for these cases but lack knowledge of the disease's cause and preventive or therapeutic measures, is enormous. The epidemic has also put tremendous pressure on the research community to orient their effort toward finding the cause and a cure. Moreover, even if an effective vaccine were available today, it would be three to five years before one could reduce the number of cases. Thus AIDS is here to stay for some time and will continue to cause tremendous concern in our community.

Fortunately, the response from a wide range of healthscience professionals nationwide has been positive and strong, as the present volume attests. The technology, talents, and expertise at work on this crisis are unmatched in the history of medicine and may ultimately bring about a major insight into the problem of AIDS. Cruel as it is, the experiment of nature represented by AIDS offers a remarkable challenge to medical science and may provide us in the end with significant new knowledge.

The history of medicine assures us that, with time and effort, this terrible mystery will, like other biological mysteries, be solved and a cure found. Meanwhile, we must continue to hope and work for that day to come. There is also some cause for optimism in the fact that we are, finally, beginning to see an increase in the number of people who have been exposed but have not developed a fatal form of the disease, suggesting that a subclinical form with recovery is possible and that the epidemic will eventually limit itself and subside.

We are still far from the final answer. But as we continue to progress toward it, an account of events that have led to our present knowledge is of great value. The authors of the present volume have compiled a detailed history of AIDS and have given a realistic picture of its dimensions. Their efforts have produced a valuable book, bringing together in chronological form the medical, social, and psychological events of the AIDS epidemic and the struggles that have been generated by them. Presenting different points of view and perspectives on every facet of AIDS, the authors have succeeded in providing us all with a comprehensive and vital document.

Bijan Safai, M.D. Chief, Dermatology Service, Memorial Sloan-Kettering Cancer Center Associate Professor, Department of Dermatology, Cornell University Medical School January 1984

### Contents

Acknowledgments ix
Foreword xi
Introduction   Dimensions of a Disease 1
1   The Opportunist 11
2   A Most Peculiar Cancer 25
3   A Delicate Balance: The Immune System 42
4   The Zigzag Course 59
5   The Clusters 82
6   New Horizons 104
7   Blood and Needles 125
8   A Child Dies 146
9   Prelude to Phase Two 167
10   The Possible and the Actual 187

11 | Differences and Similarities 195

12 | The Secondary Epidemic: The Politics of AIDS 209

Conclusion 250

Glossary 256

Annotated Selected Bibliography 269

Sources 271

Resource Directory 277

Index 289

### **Introduction**Dimensions of a Disease

Two hundred and fifty years ago glycerine was first extracted from natural fats in the form of a colorless, sweet, oily liquid and put to use in medicine, lubrication and the manufacture of explosives. Despite supercooling, reheating, and all the usual methods for inducing crystallization, glycerine remained resolutely liquid and it was assumed that the substance had no solid form. Then, early in this century, something strange happened to a barrel of glycerine in transit between the factory in Vienna and the regular client in London.

Due to an unusual combination of movements which occurred, purely by chance, in the barrel, it crystallized.

The client was probably livid but chemists were delighted and began borrowing bits from the barrel to seed their own samples which rapidly solidified at a temperature of eighteen degrees centigrade. Among the first to do so were two scientists who were interested in thermodynamics who had found that soon after their first crystals arrived in the mail and were used successfully for inducing crystallization in an experiment on one sample of glycerine, all other glycerine in their laboratory began

to crystallize spontaneously—despite the fact that some was sealed in air-tight containers.

This is a regular occurrence in organic chemistry. Yesterday something was impossible and today it is easy—partly because of the introduction of a new technique, but also in part because of the existence of a new state of mind.

—Lyall Watson Lifetide

Another crystallization has occurred, its cause unknown, its origins obscure. In different parts of the world, in diverse populations, an organism has, it seems, spontaneously changed its character. It has transformed so thoroughly that it has become unrecognizable: a microscopic *novum*. And this putative new agent has "crystallized" into a deadly new disease—Acquired Immune Deficiency Syndrome.

AIDS is intriguing to scientists, lethal to those affected, and, precisely because it is new and mysterious, frightening to us all. Through time, every person on earth will be touched in some way by what is revealed in the process of plumbing the depths of the AIDS mystery.

Thus far, the only aspect of AIDS that is clear is its *effect*: it is a disease that destroys the very mechanisms by which the body fights off disease. And this, too, is entirely unique: never before has there been a disease that attacks the immune system itself. AIDS upsets the exquisite and dynamic balance of cells that make up our basic defense against disease. AIDS disrupts the equilibrium maintained between "self" and "other," between safety and danger. AIDS infiltrates and sabotages our center-for disease control, and foments chaos—immunological anarchy.

It is thought that an unidentified strand of genetic material in its protein envelope—a virus—has caused this. In-

stead of seeking out and destroying enemies, the foot soldiers of the body's defense forces—the lymphocytes—in the blood-streams of those infected by this new pathogen are transmitting nonsensical orders back and forth. The result is biological madness: the bodies that give life to these cells and of which they are an integral part die.

Technology has enabled us to make great strides in treating disease in this century, but new diseases have arisen almost apace with those advances. Just in the past few years, we have seen Legionnaire's disease, Lyme arthritis, Kawasaki and toxic shock syndromes. The parvo virus that was known to cause sickness and death in cats recently has jumped a biological fence to infect dogs, and again to cows.

In Africa, Lassa fever, caused by a virus and carried by bush rats, infects children, who, immune to its effects, carry it home to their families. The mortality is high and Lassa is said to kill as many as 20,000 a year. No cure has been found. One hundred, even fifty years ago we would not have heard of this illness. Had a missionary contracted it, he would have died long before reports of his demise from a "fever" worked their way to the coast.

The question arises: Are we merely noticing such events because we have modern techniques with which to detect and evaluate new diseases, or do technology itself and its effects on our life-styles play their own roles in encouraging the development of diseases?

Travelers return from exotic vacations carrying equally exotic organisms, many of which either have been eliminated from Western society or have never been seen on these shores. Scattered reports of tropical bowel diseases, plague, and dengue fever filter into the Centers for Disease Control in Atlanta, Georgia. As populations become increasingly mobile,

as air travel takes us in quantum jumps from one world to another, we are likely to see other illnesses caused by agents long sequestered in remote settings, or simply never before encountered by human beings.

Can a scenario such as this explain the sudden appearance of AIDS? Could it be that affluent, highly mobile, adventurous vacationers picked up some rare organism in their travels and spread it upon their return home? Or is it possible that new immigrants—such as the Haitian "boat people"—brought with them a virus to which they were immune, but which was lethal to certain Americans?

While travel has facilitated the spread of AIDS, researchers agree that it is unlikely that the causative agent has been in hiding. Even in equatorial Africa, where some suspicion of the genesis of AIDS is focused, no previous reports of such an illness are known to physicians long treating these populations. But the "dormant agent" theory is still a possibility; no one can rule it out with certainty.

We do know that AIDS was first seen in homosexual men, and that this group has been the most severely affected by the disease. We also know that: heterosexual intravenous drug users contract the disease; men and women of Haitian nationality appear to be at considerable risk; infants likely get it from infected mothers through the umbilical cord; hemophiliacs are contracting AIDS through their use of pooled blood products; recipients of blood transfusions have gotten AIDS. We also know that women can acquire AIDS through normal heterosexual contact, that some otherwise healthy people are carriers of the pathogen and can pass it to others, and that some people who seem to belong to no risk group at all have come down with AIDS.

Although a retrovirus has been implicated as the causative agent, many scientists think that is only part of the story.

For the general public, the pressing question is: Will AIDS spread geometrically until everyone is at risk? With a latency period of perhaps as long as six to eight years, and with more than 15,000 to date having died from, or currently being ill with AIDS, no one can answer this question. Even the development of a vaccine would do nothing to help those already infected.

Furthermore, identifying the causal agent may be less than half the battle. The viral agent that causes polio had been identified long before a vaccine to prevent the disease was finally produced. Flu viruses have been isolated, and vaccines developed, yet we are still unable to keep ahead of the every-other-year flu epidemics: the viral agent seems to mutate after each outbreak and we are always a step behind. Influenza annually kills more people than AIDS has over its history.

Even so, flu is a disease we understand; it is a sickness with which we are familiar, even comfortable. If one gets flu, the likelihood is of recovery. This is not the case with AIDS: when this disease is diagnosed and confirmed, the likelihood is of death—perhaps lingering, sometimes quick.

AIDS strikes at the very heart of health—the immune system. The *symptoms* of AIDS include the disease of which we are most frightened—cancer. Another symptom is an especially virulent type of pneumonia—a disease for which we assume we had adequate medical treatment. And in the wake of AIDS come a host of esoteric agents, organisms that heretofore were seldom or never a threat to humans; now these same agents are deadly.

We are frightened because of these deaths, and because we don't know what is causing them or how to stop them. And our fear and bafflement are compounded by a unique confusion. The fact that a majority of the early victims of AIDS happen to be sexually active homosexual men has created a

### 6 | The Truth About AIDS

social atmosphere of phobia and hostility that itself may be thwarting our progress toward a solution of the medical mystery of AIDS.

"The most striking indication of the pathology of our species," said writer Arthur Koestler, "is the contrast between its unique technological achievements and its equally unique incompetence in the conduct of its social affairs." He equates this with Prometheus reaching out for the stars "with an insane grin on his face and a totem-symbol in his hands."

The physical disease of AIDS has spawned another, rapidly spreading epidemic: AIDS Hysteria. Despite the overwhelming medical evidence indicating that the disorder will remain largely confined to the limited populations that make up more than 70 percent of AIDS victims, the many "touches of the unknown" inherent in the epidemic have created panic in the general public and stigmatized those with the disease much as lepers once were singled out.

Charges have been leveled against gay men for "causing" a plague. They are accused of immorality; the disease is seen as God's righteous wrath. Some do echo the words of Anatole France, who said, "I would rather be guilty of an immoral act than of a cruel one"; but undeniably much cruelty has been done to victims of AIDS in the name of morality.

Seldom have the inner workings of scientific research been played out on such a public stage. With reported cases doubling every six months, and victims dying every week—and a potential public health problem of unprecedented proportions—researchers cannot afford to dwell over their microscopes and contemplate hypotheses. The pressure to produce quick results is intense. As quickly as a new idea or finding surfaces it is snapped up, reported, and entered into the new lexicon generated by the new disease. A phalanx of young