



## THE EARLY DAYS OF AIDS, AS I REMEMBER THEM

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In early 1981, when I was designated as surgeon general, I had never heard about AIDS. No one had heard about AIDS, and the handful of scientists who knew about immunodeficiency didn't even know what to call it, much less what it really was. AIDS entered the consciousness of the public health service quietly, gradually, and without fanfare.

In June 1981, the Centers for Disease Control published its first report of what was to become the AIDS epidemic. It concerned five "previously healthy" homosexual men who were admitted to Los Angeles hospitals with a very rare form of pneumonia, *pneumocystis carinii*. By the time the report had been published, two of the men had died. The other three died shortly thereafter. Five cases are not many, but this lethal disease is so rare that a handful of cases in a single year is like an epidemic. Soon the reports trickled in of cases occurring in other cities as well. Then, a month later, the public health service published a report that 26 young homosexual men had been recently diagnosed as having Kaposi's sarcoma, an "uncommonly reported" cancerous condition usually found, if at all, among elderly men. At the weekly meetings of what would become the top brass, it was learned that none of them had ever seen either; I had seen both and had done over a dozen lung biopsies on babies receiving cancer chemotherapy.

From that small beginning the cases mushroomed into the AIDS epidemic of the late 1980s. The public health service had never seen it before, and so it was given a somewhat awkward title, the "acquired immune deficiency syndrome". For a short time some people called it GRID—Gay-Related Immune Deficiency—but when there were cases in non-homosexuals, it was called A.I.D.S., and finally just AIDS, and it has been that ever since. By August of 1981, I and others who were paying attention to the unusual news from CDC learned that there were 108 cases of AIDS reported with 43 dead. I knew we were in big trouble. And there was nothing I could do about it. I was not yet the surgeon general, and all through that 1981 summer and autumn I was preoccupied by my long struggle to win confirmation as surgeon general by the Senate. But I realized that if there ever were a disease made for a surgeon general it was AIDS.

But, for reasons of intra-department politics that I can still not understand fully, I was cut off from AIDS discussions and statements for the next five years. My exclusion from AIDS was just another facet of Washington politics, especially the disturbing interplay between politics and health, which—no surprise—still goes on today. I had to be content to learn about AIDS on my own, from the newspapers, internal documents of the public health service, reports from CDC such as *Morbidity and Mortality Weekly Report*,

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and discussions with colleagues. I did manage to make a statement – not proven for several years. I said something like this: "CDC has reported 5 patients with pneumocystis, all of whom have already died and later reported 26 more with Kaposi's sarcoma. All patients were previously healthy homosexuals. Knowing what I do about forced sodomy in jails and prisons, what are you planning to do—solitary confinement? —Put patients with the same diagnosis in a common cell?" They laughed at me. Two years later when we knew a little more, a municipal jail in the U.S. reported something well over 50 percent of paroled persons were discharged home with what we then called a positive HIV blood test.



While the PHS brass were laughing at me for my concern about the spread of whatever it was we were talking about, newspapers all over the country were discussing my incompetency if I were to be confirmed by the Senate as surgeon general.

There were two reasons why it took a while for public health authorities to get a handle on AIDS in the beginning. One was the relatively few trained clinicians and researchers familiar with these rare diseases that were cropping up in Los Angeles, San Francisco, and New York. The second reason was that the first patients with those conditions were homosexual men, most of whom patronized physicians and clinics that were more understanding of the so-called "gay lifestyle." In making that choice, these men effectively placed themselves outside mainstream clinical medicine and, therefore, they were more difficult to know, to reach, and to help. As a result, our first public health priority—that is, to stop further transmission of the AIDS virus—became needlessly mired in the homosexual politics of the early 1980s.

We lost a great deal of precious time because of this, and I suspect we lost some lives as well. By July 1985, CDC had reported 11,737 AIDS cases, with 5,812 deaths. Just a week later the numbers had risen by about a hundred each for cases and deaths. At about the same time, the death of Rock Hudson (the first national figure to die of AIDS) raised further public concern about the disease and for the first time, because of Reagan's friendship with his fellow actor, seemed to touch the White House, even if indirectly. Also in 1985, as the public health service and other branches of the medical community learned more about AIDS, a weapon in the struggle against the strange disease was provided: a test to identify the presence of antibodies to the HIV in the blood supply for transfusion. We couldn't see the virus, but saw its footprints, or its shadow.

In spite of charges of "foot-dragging" we learned as much about AIDS in 6 years as we learned about polio in 40 years. Although we acknowledged that there was much we didn't know about AIDS we had made extraordinary progress in our understanding of the syndrome. We identified the virus, named it and renamed it. We understood the epidemiology among homosexual men and IV drug abusers. We learned of

homosexual practices hitherto barely mentioned, and we understood the extent of homosexual promiscuity.

We identified antibodies to the AIDS virus and developed a screening test on the basis of the detection of these antibodies. This made the blood supply safe for transfusion. We learned how to kill the virus in blood products and make clotting factors made from blood safe for hemophiliac therapy. Above all we were concerned about how the disease is transmitted. We learned that although the virus had been identified in several body fluids, it seemed to be transmitted only through blood and semen.

Researchers were very cautious. For example, Tony Fauci, Director of AIDS Research at NIH, insisted we check out any study that didn't seem to rule out spread of AIDS by casual contact. But gradually a convincing body of research led us to some important conclusions. It was clear that in spite of all kinds of unsubstantiated claims about mosquitoes and toilet seats, AIDS could be transmitted in only four ways: 1) through sexual contact, 2) through blood contact associated with IV drug use, 3) through pregnancy or delivery contact between an AIDS-infected mother and her infant, and 4) through transfused blood. The most important thing we knew was the deadliest news: if you had AIDS, your chances of surviving the next two or three years were not very good, and the chances of surviving any longer than that almost nil.

At an invitational meeting in July 2010 at Dartmouth Med School, it was clearly shown that the major transmission of HIV in the previous year had been through heterosexual contact. The research was intracellular, intramolecular and fascinating. Not long after the blood test was announced, my personal distance from AIDS information and policy came to an end, when President Reagan asked me to write a report on AIDS to the American people. And then for the next two years AIDS took over my life. I had heard the rumors for a week or so. At the end of January 1986, at a dinner hosted by then Treasury Secretary Jim Baker and his wife, Susan, at the Cincinnatus Club, two of the White House staffers present slipped up to me and whispered, "You're in the State of the Union message." They said that the President was going to ask me to write a report on AIDS. I thought this unlikely because about 1500 issues are suggested for inclusion in the State of the Union message, and I thought that even if the President might be ready to



finally talk about AIDS, his advisors were not. My wife and I watched the 1986 State of the Union speech on television and it was such an upbeat, frothy speech that we knew halfway through that the President would never mention AIDS. He didn't, and I said to Liz before going to bed that night, "I guess I'm off the hook on writing that report."

Then, only a few days later, on February 5th, President Reagan made an unprecedented visit to the Department of Health and Human Services at the Humphrey building. In the course of his remarks he said that AIDS was to be a top priority in the department and he looked forward to the day when there would be a vaccine. He then announced that he was asking the surgeon general to prepare a special report on AIDS. At the Baker's party, a member of the cabinet accosted me:

Cabinet member: *"Dr. Koop!"*

Koop: *"Yes Sir!"*

Cabinet member: *"You weren't very fair to us at the cabinet meeting where you talked to us about AIDS."*

Koop: *"How come?"*

Cabinet member: *"You know there was a lady present (Liddy Dole, wife of Sen. Dole, then Secretary of Transportation), and some of us had questions we couldn't really raise in a lady's presence."*

Koop: *"Do you know what Mr. Dole's job is? He's a senator; that's his government elected position! Do you know how he makes his money? He is the spokesman on TV for Viagra ads; I suspect there is very little, if anything, of sexual matters that haven't been discussed by the Doles!"*

I have not seen nor spoken to him since. That was it. There was never any formal request from the White House. It's a good thing that I was there . . . and paying attention!

I assumed that the report was to be in simple language for the average citizen, that it was to allay the panic that was spreading among people who were in no danger of getting AIDS, and to warn those engaged in high risk behavior what the inevitable outcome would be if they encountered the virus of AIDS. But I knew that the government clearance process could ruin any report I would write. I needed the authority to write it on my own. And I got that

authority from the newly appointed Secretary of HHS, Otis Bowen, for whom I had great admiration and respect – and still have! A former, three-time governor of Indiana and a physician, Bowen was initially regarded as a mere caretaker head of HHS. But Bowen would serve with distinction as Secretary of HHS longer than anyone in the history of the department, a true public servant. He certainly was at the top of Reagan's cabinet appointees, even though his quiet and unassuming style did not attract the attention he deserved. Otis Bowen gave me the green light I needed. I selected two commissioned officers to help me. Their names were not revealed then or since.

Writing the AIDS report, like much of my work in Washington, amounted to walking a tightrope. I needed to be in touch with all national groups that were concerned about AIDS. I wanted to make sure they knew what I was doing, and I wanted none to say, after the report was published, that they had been blind-sided or kept in the dark. Equally important, I needed all the help I could get, and I valued their input and advice.

But, at the same time, I had to make sure that the report was independent, objective, that it was my report. To do that I had to distance myself from the same groups that provided information and counsel. A few meetings were especially helpful. For example, the information provided by the National Hemophilia Foundation was critical. Their experience with hemophiliacs who had become infected with AIDS allowed these tragic cases (90% of severe hemophiliacs would eventually become infected with HIV) before we had the blood test. The hemophiliacs made a major contribution to our understanding of the disease. We also learned about the strength of young people who lived throughout their lives with two diseases, hemophilia and AIDS, as well as with the fear and consequences of discrimination. The hemophilia experience nailed down the evidence that AIDS was not spread by nonsexual casual contact. Six hundred families of hemophiliacs were studied. Their members, with a two-year exposure to the virus, touched each other, used the same utensils, kissed each other and shared razors without passing the virus. Even the 7% who shared toothbrushes saw no transmission of the virus from infected patients to their toothbrush partners. This was very important.



This—and a number of other studies—meant that AIDS was not transmitted by casual contact. Therefore, most Americans were not at risk, if they did not engage in high-risk behavior with sex and/or drugs. This also meant that persons with AIDS should not suffer discrimination, that the strident calls to quarantine them or even deny them housing, insurance, employment or public schooling were wrong.

In August 1986, I began to write the first draft of the AIDS report. I wrote and I rewrote, usually in the evening at the stand-up desk in the basement of my house on the NIH campus. After the 16<sup>th</sup> draft, I asked Tony Fauci to read it, and he made some excellent suggestions. We also called on the wives of several commissioned officers to do the same. The official American response to AIDS, as far as the government was concerned, hinged on two meetings of the cabinet. The first, just before the AIDS report was released, involved only those cabinet members dealing with domestic affairs, the Domestic Policy Council. The other, in May 1987, would involve the entire cabinet and the President. In each meeting I had to skate fast on thin ice to get by political appointees who placed conservative ideology above saving lives. Knowing the way the Domestic Policy Council worked, I could see them nit picking the report to pieces, and soon we'd have a health report written by political advisors, if we ended up with any report at all. I also knew these were people who did not like to spend money.

So I decided to take a psychological gamble. It had been our plan to print this report as a brochure on cheap paper, so we could print two to three million copies. But, I also ordered one thousand copies printed on the best quality glossy stock, with a cover in the royal blue of the public health service, its seal printed in shining silver, and across the top, the title: *Surgeon General's Report on Acquired Immune Deficiency Syndrome*. I figured that if the Domestic Policy Council were handed a pamphlet shrieking expensive paper and printing, they might be disinclined to make changes because of the cost of reprinting. I think my first remark took them by surprise. "From what I read in the newspapers, this room has great leaks in it, and I would be very unhappy if this report were to reach the press before it was released by me. Therefore, I am handing out

numbered copies of the surgeon general's report on acquired immune deficiency syndrome – and I hope you will not be insulted if I tell you that I expect to collect each of them at the close of this meeting." A few eyebrows went up. I reviewed the report page-by-page, but in a rather superficial manner. There was little discussion. There was not a peep about the cost of the brochure! I knew it had not been absorbed in depth by anyone present.

At long last, on October 22, 1986 I called a press conference to release the AIDS report. Of all the things I said, only two words seemed to be remembered: sex education, and the next few days were spent fending off press questions about my ideas on when sex education should begin, and all the questions that come to mind if your interest is in sex education. Many of the larger issues of AIDS in the report seemed eclipsed by this distraction. In the meantime, having failed to come to grips with the AIDS report when they first read it, the political meddlers in the White House tried to bottle up the report. In an unusual move, two White House staffers came to see me and "wondered" if I didn't want to "update" the report. Hear that as "Don't you want to rewrite the report and leave out the word 'condom'?" The report, then only a few weeks old, did not need "updating"; it doesn't need "updating" even today, except for drug prescriptions. Of course I refused!

The condom story has its own life and substance. Half the people who spoke of them called them condrums. Each morning in those days I had breakfast with my wife then left the home on the NIH campus about 7am for the Humphrey building. My wife was a great sounding board for what I had in mind to do next. One morning she asked what I was doing that day, I replied: "Giving testimony before a congressional committee on the advertising of condoms for AIDS prevention on TV." She replied "I'm glad your mother's dead!"

Meanwhile the presses were turning and the mail trucks running and the report went out. At last, the people of the country knew what was myth and what was fact about the AIDS epidemic, and they knew it in plain English. We also had a Spanish edition. But people wanted to hear more, and I found myself deluged by requests from all over the country to speak at various meetings, conventions, and even to combined sessions of state legislatures. America



finally was getting mobilized against AIDS. And a new and surprising band of opponents mobilized against me. Suddenly, I found myself praised by my former liberal adversaries and condemned by my former conservative allies. Everybody, or at least those who didn't know me, said that I had changed. Conservatives said I had changed, and they were angry. Liberals said I had changed, and they were pleased. But I hadn't changed at all. All the fuss surprised me. I just did what I had always done as a doctor. My whole career had been dedicated to prolonging lives, especially the lives of people who were weak and powerless, the disenfranchised who needed an advocate: newborns who needed surgery, handicapped children, unborn children, baby does, and people with AIDS.

I didn't like having to talk about condoms. It was difficult for an old-timer then 70 years old, about to celebrate his 50<sup>th</sup> wedding anniversary, to talk about condoms. I never mentioned the use of condoms as a preventive measure against AIDS without first stressing the much better – and much safer – alternatives of abstinence and/or monogamy. But if the general public seemed to be making substantial progress in learning about AIDS, the White House wasn't. I quickly saw that the Reagan White House, including the President himself, usually reasoned anecdotally instead of examining the evidence and drawing conclusions. In one of many examples, at another meeting of the working group on health of the Democratic Party caucus, one member, a nurse, no less, said that there were many people in the country who thought that AIDS was transmitted by cats, mosquitoes, door-knobs, toilet seats, and the like. "Who was to know," she said, "maybe they are right and the government is wrong." These discussions about AIDS with a variety of government figures depressed me more than ever about the lack of intelligence among some people in high places.

The major problem was that the President was not out in front offering the leadership that only he could provide. At least a dozen times I pled with my critics in the White House to set up a meeting between the President and me so he could hear my concerns about America and the AIDS epidemic. And for months I had tried to cover for the embarrassing silence of the oval office on the scourge of AIDS. I kept telling myself the President had to speak out soon. Finally, in April

1987, the President mentioned AIDS for the first time in public, touching upon the epidemic briefly and superficially in his speech at the Philadelphia College of Physicians. When a number of reporters were shouting questions to him as he went up the ramp to Air Force One, he turned on the top step and said, "Just say no". That night, Tom Brokaw reported that the President had not even read the surgeon general's report on AIDS.

By the spring of 1987, it became obvious that one issue would shape official AIDS policy in the United States, and that issue was testing blood of patients for AIDS. At first it made sense to many people: with a killer disease on the loose, just test everybody to see who has it. But a little more thought on the issue revealed the shortcomings of that simplistic solution. First, what would you do with those who tested positive? Of course, I'd already heard from those congressmen and others who wanted to kill them or put them in concentration camps. And there was that little issue of the Constitution, which didn't allow you to round up people because they were ill.

AIDS became an issue not only of health, but also of civil rights. Widespread AIDS testing could result only in widespread discrimination against people who tested positive. Already the American people, at least those Americans who thought with justice and compassion, were horrified by the story of Ryan White, driven by fear and hatred from his school and town in Indiana. And then there was the Ray family in Florida whose three little hemophiliac boys infected with HIV by blood transfusion through no decision they made, suffered not only humiliating discrimination, but saw their house burned down by arsonists, presumably fearful and hating neighbors. Above all, mandatory AIDS testing would drive underground, away from help and counseling, the AIDS-infected people who needed help, not only with their own health, but needed help in reforming their behavior so they would not infect others. Driven underground, these people would only continue to spread the disease. But I knew testing would serve its purpose only if it were voluntary and absolutely confidential.

Amidst the controversy about testing, at last, there would be a cabinet meeting devoted primarily to AIDS. As far as I know, it would be the only US cabinet meeting at which AIDS was discussed. That issue was



whether the President was going to follow the advice about testing as offered by his health officials or if he would choose the plan of mandatory and widespread testing advocated by some of the political hacks in the White House. At the cabinet meeting, I was sitting in the second row, and unobtrusively, I pushed my chair back so I was slightly behind the two people seated on either side of me. That way no one could see my face except the President. Whenever the President had a question that I wanted to answer, or whenever a cabinet member made a statement I wanted to reinforce or rebut, I raised my right index finger beside my nose and almost imperceptibly nodded toward the President. He acknowledged me on each occasion without anyone knowing I had really asked to speak, because the President, each time said something like, "I'd like to hear from Dr. Koop on that", or "Would you care to comment on that, Dr. Koop?" That system worked eight times; there were no misses. And I like to think that it steered the President toward his decisions to espouse the precepts of public health service on AIDS. Testing would remain voluntary, and confidential. Testing should come under review again in view of the persistence of the epidemic. I was so pleased by the outcome, that when, shortly after, I attended an amfAR function, I barely noticed the pickets who were shouting obscenities as they milled around carrying placards: "quarantine Manhattan island", "burn Koop", and other encouraging messages. Our position against mandatory premarital testing was eventually vindicated by the 2 states that adopted it, Illinois and Louisiana, because they later repealed their testing laws. The AIDS report had done its job: it had made accurate information on AIDS available to the American people. Even so I was burned in effigy in Georgetown.

But, we knew from the start, that making the information available did not ensure that the people would get it. So, I decided to send you a letter, hereafter called "the mailer". Incidentally, I was encouraged along the way by France and Australia's reprinting parts of my original report on AIDS. We in the public health service had discussed several times the idea of mailing a copy of the report to everyone on the IRS mailing list, the largest in the country. It

was all set to go by May 1988: the largest print order, the largest mailing in American history: 107,000,000 copies. There was only one small mistake in the mailer, and it was made during the layout. The part of the mailer explaining that you could not tell by looking at someone whether or not he or she had AIDS was entitled "This Is What AIDS Looks Like". Inadvertently, right next to it, we had placed the picture of Tony Fauci as an illustration of another text. Nevertheless, what the reader saw was Tony's picture with a caption "This Is What AIDS Looks Like!"

The first phase of America and AIDS, from the first cases in 1981 until the AIDS report in 1986, was marked by mystery, fear, suspicion, judgment, the unknown. The second phase, and the time where I made my contribution, saw health officials overcome considerable opposition—some misguided, some mean-spirited—to at last bring the facts of AIDS before the American people: in the AIDS report, the AIDS mailer, and the hundreds and even thousands of articles and television programs about AIDS. The press did a commendable job of communicating the issues of AIDS. The American people learned that except for babies who got AIDS from their mothers, except for innocent sexual partners of AIDS carriers who took no precaution, that in order to get AIDS you had to engage in risky behavior, behavior that many Americans thought illegal or immoral in addition to being risky. And in that second phase of AIDS, Americans sorted through the issues of testing, discrimination, and civil rights, and in general rejected the bad laws and approved the good ones, assuring people who did not practice high risk behavior that they were protected from the disease, and also in general protecting the civil rights of those who contracted AIDS. But the disease, the epidemic, continued to grow in American society, claiming more victims each month. And so we entered the third phase of America and AIDS, the phase when the society, the health care system, and probably each American will have to come to grips with people dying of AIDS. But with a formerly acute fatal disease becoming chronic and some AIDS patients living out their hitherto normal life span, being burned in effigy doesn't hurt a bit. Each of us must keep HIV/AIDS from becoming the forgotten epidemic.