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Journal Publishes Dr. Koop's Personal Account of the AIDS Controversy *Paper Gives Details of One of the Most Significant Public Health Battles in History*

WASHINGTON, DC (March 31, 2011) – The nation's war against AIDS began 30 years ago with a report that five gay men in Los Angeles were dying from *Pneumocystis Carinii* pneumonia, a disease so rare that a handful of cases in a single year is like an epidemic. Now, former Surgeon General Dr. C. Everett Koop -- the official who witnessed these early deaths and charted the nation's policies on HIV/AIDS -- is making public his personal account of what took place in the early days of AIDS, naming names and providing the behind-the-scenes details of one of the most significant public health battles in the country's history.

Published in the March 31 issue of *The Annals of the Forum for Collaborative HIV Research*, Dr. Koop's paper -- *The Early Days of AIDS, As I Remember Them* -- is based on what the former Surgeon General described as his "last major address" on HIV/AIDS, which was presented in Washington on November 18, 2010 before 350 HIV researchers, health care providers, policymakers and advocates attending the *2010 National Summit on HIV Diagnosis, Prevention and Access to Care*. With a foreword from Dr. Anthony Fauci, Director of the National Institute of Allergy and Infectious Diseases (NIAID), Dr. Koop's personal account chronicles the very real challenges facing the public health community at the beginning of the AIDS crisis and presents a candid assessment of how a small number of cases mushroomed into the AIDS epidemic of the late 1980s.

The Annals of the Forum for Collaborative HIV Research is a peer-reviewed journal published by the Forum for Collaborative HIV Research that disseminates consensus reports and proceedings, recommendations and opinions addressing current topics in HIV/AIDS prevention, treatment and care. Dr. Koop's paper is available online at http://hivforumannals.org/index.php/annals/article/view/86/pdf_5

"This is a story that has begged to be told," said Veronica Miller, Ph.D., Director of the Forum for Collaborative HIV Research, which also hosts the biannual HIV summits. "We will only be successful in overcoming today's challenges in fighting HIV/AIDS by heeding Dr. Koop's frank message that we not forget that the epidemic is still here and is growing insidiously."

Providing lessons learned from the past, Dr. Koop's paper chronicles the developments and controversies that marked the early AIDS crisis from 1981 to 1989, which he refers to as two "phases of America and AIDS." Starting with the "the first phase of America and AIDS" -- from 1981 until the release of the *Surgeon General's Report on Acquired Immune Deficiency Syndrome* in October 1986 -- Dr. Koop describes a climate "marked by mystery, fear, suspicion, judgment and the unknown" when political leaders attempted to quarantine AIDS patients in San Francisco and New York City and to deny these individuals housing, employment and even access to public schools. "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," Dr. Koop writes.

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These same fears, Dr. Koop surmises, played a large role in the “intra-department politics” at the Department of Health and Human Services (HHS) and the decision to exclude him from the Reagan Administration’s discussions, deliberations and public statements about AIDS for a five-year period (until 1986). As Dr. Koop described his isolation at the time, “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 Reports*, and discussions with colleagues. ...I knew we were in big trouble. And there was nothing I could do about it.”

In his foreword, Dr. Fauci, who was a young physician at the National Institutes of Health (NIH) in 1981 and became Dr. Koop’s personal physician at the time, discusses the stress Dr. Koop was under and the impact on his physical health. “After being nominated by President Regan to be the 13th Surgeon General of the United States, he (Dr. Koop) endured months of controversy and Senate hearings. This resulted in great personal distress: his (Dr. Koop’s) blood pressure rose, he could not sleep, he was feeling terrible and could not figure out what was wrong with him. He was the greatest surgeon in the world at the time but this was not a surgical problem.”

But even as Dr. Koop endured this long and stressful confirmation process, he realized that no one in public health or medicine had ever seen a syndrome like the AIDS virus before. He recounts: “I realized that if there ever were a disease made for the Surgeon General, it was AIDS.”

After being kept on the sidelines for five years, Dr. Koop writes candidly about how he learned in 1985 that he would be asked to write the landmark *Surgeon General’s Report on Acquired Immune Deficiency Syndrome*. President Reagan made an unprecedented visit to HHS after his longtime friend Rock Hudson died of the disease and during a speech to the HHS employees, the President announced he would ask the Surgeon General to prepare a special report on AIDS. “That was it,” Dr. Koop states. “There was never any formal request from the White House. It’s a good thing I was there (at the HHS meeting)...and paying attention!”

Once Dr. Koop was tasked with writing the AIDS report, he confronted another political challenge -- the clearance process for reviewing public documents. “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 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.”

Dr. Koop’s strategy was to go to the newly appointed HHS Secretary, Otis Bowen, whom Dr. Koop describes as a “true public servant,” and ask for the authority to write the report himself. He says of this encounter: “Otis Bowen gave me the green light I needed. I selected two commissioned officers (in the Public Health Service) to help me. Their names were not revealed then or since.”

Now authorized to write the report himself, Dr. Koop recounts how his work “amounted to walking a tightrope” because he felt it necessary to consult with all national groups concerned about AIDS while also distancing himself from these organizations so the report would be viewed as independent and objective. However, Dr. Koop credits the information he received from these meetings as eye opening. One such example he cites was a study commissioned by the National Hemophilia Foundation, which showed that AIDS could not be spread by nonsexual casual contact.

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“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,” explains Dr. Koop. “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.”

Dr. Koop recounts spending long hours in his house on the NIH campus writing the report at a stand-up desk in the basement. After reworking the document multiple times, Dr. Koop showed the 16th draft to Dr. Fauci, then Director of AIDS Research at NIH, as well as to the wives of several commissioned officers of the Public Health Service. But the real challenge for Dr. Koop was not drafting the report; it was getting final approval for the report from top Administration officials. This entailed presenting the report at two meetings of the President’s Cabinet -- the first with the Domestic Policy Council and the other involving the entire Cabinet and the President.

Recounting how he navigated these meetings, Dr. Koop writes, “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.”

According to Dr. Koop’s paper, the Surgeon General recognized what he was up against and decided to take a “psychological gamble.” Knowing that members of the Domestic Policy Council “did not like to spend money,” he printed 1,000 copies of the report on expensive glossy paper with the Public Health Service seal embossed in shiny silver – even though he really intended to print the report as a brochure on inexpensive stock. “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,” he writes.

Dr. Koop then recounts how he handed out numbered copies of the report to the members of the Domestic Policy Council with the proviso that to keep the report from leaking to the press, he intended to collect all copies at the end of the meeting. Describing how this gamble paid off, Dr. Koop writes how he reviewed the report page-by-page, but in a rather superficial manner. “There was little discussion. There was not even a peep about the cost of the brochure! I knew it had not been absorbed in depth by anyone present.”

Once the report had been cleared for publication, Dr. Koop’s next battle came when he released the AIDS report on October 22, 1986 at a Washington press conference and mentioned the words “sex education.” Here, he describes how “the political meddlers in the White House tried to bottle up the report” by suggesting that he “update” the report, which Dr. Koop inferred to mean leaving out the word “condom.”

Dr. Koop refused this request but was still surprised by the reaction of political leaders on both sides of the aisle. “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,” he writes.

But the real problem at the time, reports Dr. Koop, was the lack of support from the White House. As he states with great candor, “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.”

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Dr. Koop also speaks with great candor about the attempts by some members of Congress to require mandatory testing for AIDS, which in 1987, threatened the civil rights of those infected with the virus. Amid this controversy, Dr. Koop recounts a Cabinet meeting where the President had to decide between the advice offered by Dr. Koop and other health officials to offer testing on a voluntary and confidential basis or to require mandatory, widespread testing advocated by some members of the White House staff.

“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,” writes Dr. Koop. “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 imperceptively nodded toward the President. He acknowledged me on each occasion without anyone knowing I had really asked to speak...” As described by Dr. Koop, President Reagan asked to hear from Dr. Koop on eight occasions and then agreed that testing would remain voluntary and confidential.

Dr. Koop calls his time in confronting the AIDS epidemic from 1986 to 1989 as the “second phase of America and AIDS,” when “Americans sorted through the issues of testing, discrimination and civil rights, and in general, rejected bad laws and approved 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.”

Now, the former Surgeon General has set his sights on the “third phase of America and AIDS” and a time when a formerly fatal disease has become a chronic condition and people with HIV can live a near normal life span. Despite the tremendous progress over the last 30 years, Dr. Koop states that the dual challenges of stigma and complacency remain significant obstacles to getting more people with HIV tested and linked into care. Accordingly, Dr. Koop is calling on today’s public health leaders to be aggressive in confronting these challenges, which he states are as dangerous today as the irrational fear in the first days of the AIDS epidemic.

On a very personal note, however, Dr. Koop also admits wryly that given how much progress has been made in combatting HIV/AIDS in this country over the past 30 years, “being burned in effigy doesn’t hurt a bit.”

About the Forum for Collaborative HIV Research

Now part of the University of California (UC), Berkeley School of Public Health and based in Washington, DC, the Forum was founded in 1997 as the outgrowth of the Keystone Center's report "The Keystone National Policy Dialogue on Establishment of Studies to Optimize Medical Management of HIV Infection," which called for an ongoing collaboration among stakeholders to address emerging issues in HIV/AIDS and set the research strategy. Representing government, industry, patient advocates, healthcare providers, foundations and academia, the Forum is a public/private partnership that is guided by an Executive Committee that sets the research agenda. The Forum organizes roundtables and issues reports on a range of global HIV/AIDS issues, including treatment-related toxicities, immune-based therapies, health services research, co-infections, prevention, and the transference of research results into care. Forum recommendations have changed the ways that clinical trials are conducted, accelerated the delivery of new classes of drugs, heightened awareness of TB/HIV co-infection, and helped to spur national momentum toward universal testing for HIV. [http:// www.hivforum.org](http://www.hivforum.org).

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