Documenting “A Disaster for Society”: AIDS and the Office of NIH History

Michele Lyons, Curator, NIH Stetten Museum
National Institutes of Health
MeMA/ALHHS Meeting, April 2015, New Haven
“I made the decision that we would have to switch over to research on this disease [AIDS] because, as every month went by, I became more convinced that we were dealing with something that was going to be a disaster for society.”
- Dr. Anthony S. Fauci
# AIDS Memorandum

**Acquired Immune Deficiency Syndrome**

**National Institute of Allergy and Infectious Diseases**

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## INTRODUCTION

This is the first issue of the AIDS Memorandum. This Memorandum is being published by the National Institute of Allergy and Infectious Diseases to provide a centralized forum for the rapid but informal dissemination of new clinical and experimental findings on AIDS. It is also intended that, in the Memorandum, novel ideas about the disease can be aired among members of the wide scientific audience concerned with this syndrome. To date, despite the diversity of approaches to research and treatment which have been taken by immunologists, epidemiologists, oncologists, virologists, parasitologists, internists, molecular biologists and others, AIDS remains a mysterious, devastating, lethal disease.

The AIDS Memorandum is modeled on other scientific memoranda, such as the Hepatitis, leprosy, and Interferon Scientific Memoranda. The formats used for all memoranda include certain specific features which distinguish them from the standard journals with which every researcher is familiar. Because AIDS is a uniquely political disease, the format and the ground rules (see Page 2) devised specifically for the AIDS Memorandum consider, in addition, how proper use and accurate representation of information printed in the Memorandum can be guaranteed such that the professional interests of contributors will be protected.

The AIDS Memorandum will print preliminary data, negative findings, single case reports, and other types of material not ready or, in some cases, suitable for publication in formal journals. The expeditious sharing of these types of data may serve an important role in the eventual development of regimens for successful disease control. Material
Dr. DeWitt Stetten, Jr. and Jane Stetten cut the ribbon on the museum’s first exhibit, May 1987.
MEMORANDUM

MEMORANDUM

DEPARTMENT OF HEALTH AND HUMAN SERVICES
PUBLIC HEALTH SERVICE
NATIONAL INSTITUTES OF HEALTH

To: Mr. J. F. Freeman, Jr.
Mr. J. N. Gossett
Mr. W. H. Greene
Mr. V. Belks

抄送: Kupfer's Sarcoma Studies

October 15, 1952

The recent NCI-ECG workshop on Kupfer's sarcoma was very stimulating. I was very impressed, in particular by the data presented by the NIH group. The interdisciplinary approach that they have developed is exceptional, and the amount of data they have accumulated, given the short time they have been at it, is impressive. As funding is being developed by NIH for further studies on this new disease, I think it is very important that we dream of projects that they (1) enroll patients on a common protocol; (2) systematically study patients, employing virologic, immunologic, histopathologic, and endocrinologic approaches; and (3) enroll all patients in the U.S. case-control study. It would be advantageous if centers in one geographic area might be comparing, for a limited number of cases hand together to maximize the potential for etiologic study. Thus, a consortium of universities could blend their talents in a comprehensive etiologic and therapeutic program.

As I mentioned to you, Dr. Jim Bostick has pulled together some fascinating data on a group of clinically unaffected homosexual men. His results and intercations are striking for your information. Since these are unpublished and preliminary data, they should be held in confidence.

If any of our group can be of assistance in developing strategies (Jim has already been advising NCI), please feel free to call upon us.

cc: Mr. J. F. Freeman, Jr.
Mr. J. N. Gossett
Mr. W. H. Greene
Mr. V. Belks

To: Richard

Heard your proposals at Kupfer's, interesting.
AIDS History Group Newsletter
Summer 1996

Syracuse Meeting in Buffalo

A short ABC business meeting will follow the presentations and discussion. Please bring new suggestions for a documentary project that should be undertaken but has not yet been started. Persons who can't attend should send suggestions to whammar@nih.gov. We look forward to seeing you in Buffalo.

San Francisco Bay Area Oral History Project
The San Francisco Bay Area AIDS Oral History Project, sponsored by the University of California at Berkeley and San Francisco, and conducted by Sally Smith Hughes, is an ongoing series of interviews documenting the biomedical response to the San Francisco AIDS epidemic. The project collaborates closely with the UCSF Librarians' AIDS History Project which surveys and collects regional AIDS-related documents.

The three phases of the oral history project consist of two to six hour interviews with 15 University and health department physicians and scientists. Volumes one and two of the interviews are available at USF or for purchase at cost. Phase 2 of the project consists of six to eight hour interviews with nurses associated with AIDS activities as UCSF, San Francisco General Hospital, and the Whitman-Walker Association. Phase 3, begun in March 1996, will consist of interviews with 15 practitioners with private HIV practices. The focus of the fifth year phase is 1981-1984. Phase 4 will be focused in time to include documents of community-based clinical trials and other research developments. For information about purchasing volumes, contact:
The Regional Oral History Office
116 Library
University of California
San Francisco, CA 94140
AIDS and the Historian

“Should we try to anticipate the questions that future scholars will want to ask and to formulate collection strategies on the basis of speculation?”
p. 34

“Should AIDS historians distance themselves from current events so as to be purely objective, or be responsive to current events so as to present a comprehensive view?”
p. 32

The conference was sponsored by the AAHM AIDS History Group, ONH, NHLBI, NIDR, NLM, and UCSF.
“Last month, Dr. Edward N. Brandt Jr., assistant secretary for health, directed the Public Health Service to increase activities related to AIDS. The supplemental money provided for 10 NCI-supported investigators is in addition to that included for current NCI research as well as $2.205 million in FY ‘93 funds set aside for research in this area.”

Department of Health and Human Services Press Release, September 20, 1982
“Most people think HIV is only a problem in big cities. Unfortunately, I was one of those people.”

Krisa Blake, HIV Positive

From the NLM AIDS Poster Collection:
http://ihm.nlm.nih.gov/luna/servlet/view/all/what/Posters/
Drs. Victoria Harden (ONH), Donald Lindberg (NLM), and C. Everett Koop at the “AIDS and the Public Debate” conference sponsored by pharmaceutical companies Merck, Hoffmann-LaRoche, SmithKline Beecham, and Upjohn. NLM and NMHM provided space and support, as did William and Audrey Hefland.
The introduction to *AIDS and the Public Debate* noted: “AIDS has had a history of little more than a decade, but its impact on society has been so significant and its effects so diverse that it is not too early to begin to analyze the ways in which this disease has shaped our world and our reactions to it.”

Harden’s chapter can be found at [http://history.nih.gov/NIHInOwnWords/docs/page_34.html](http://history.nih.gov/NIHInOwnWords/docs/page_34.html)
AIDS at 30
A History
Victoria A. Harden
http://history.nih.gov/NIHInOwnWords/index.html

Transcripts of Oral Histories

Timelines

Document Archive

Image Archive

Links
Dr. Anthony Fauci’s Carl Zeiss Inc. Universal Microscope 0433
Abbott Laboratories Human T-Lymphotropic Virus Type III EIA Kit
Coulter Corp. Antibody to HIV Type 1 p24 Antigen (Murine Monoclonal) ELISA Test System
Burroughs Wellcome Retrovir (Zidovudine) Capsule Bottle
Recently, the medical community has noted the occurrence of a very serious disease known as Acquired Immune Deficiency Syndrome (AIDS). The Center for Disease Control has documented an increasing number of cases of this disease throughout the country.

As the name indicates, the disease seems to disrupt the patient's immune system, that is, impair their ability to fight off disease. Very little is known about the disease - about its causes - except that it is known to be fatal and that currently specific treatment is unknown.

In the past, you have helped us to help others through your plasma donation efforts. We are now faced with a situation in which only YOU can help us insure a safe product to those whose lives depend on it. Because of our goal of reducing the possibility that this disease might be transmitted through our products, we are now asking for your cooperation.

Until the cause of this disease is determined, we are asking people to NOT DONATE BLOOD OR PLASMA who are a part of any of the following groups:

1. Persons with signs and symptoms suggestive of AIDS
2. Sexually active homosexual men with multiple partners
3. Sexually active bisexual males (one having sex with both sexes) with multiple partners
4. Haitian entrants into country last 13 years
5. Frequent and past abusers of intravenous drugs
6. Sexual partners of individuals at increased risk of AIDS

Please inform the medical historian if you are a part of these groups. Our physician is also available to answer any questions which you might have concerning AIDS. Thank you for your cooperation.

I hereby certify that I have read and understand this document and to the best of my knowledge I am not a part of any HIGH RISK GROUP.

DATE: [Signature]

Witness:

1983

Blood Donor Alert Information

1993
“I can say more people came out of the woodwork wanting to sign that letter than I thought were working at HHS.”

Surgeon General C. Everett Koop,
AIDS and the Public Debate p. 15
Eclipse Enterprises AIDS Awareness Trading Cards with Condom, 1992
Artists Charles Hiscock and Greg Loudon

A complete set had 110 cards.
May 21, 1990
ACT-UP “Storm the NIH” Demonstration
25 Years of AIDS Research

25 Years of AIDS Research: June 5, 2006
http://videocast.nih.gov/summary.asp?Live=5028&bhcp=1
'AIDS in New York: The First Five Years' at New York Historical Society
What have we learned?

Don’t assume someone is collecting the history of a particular crisis in your institution.

Don’t wait to collect.

Use and make contacts.

Collect all sides of the story.

Don’t forget the science!