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Congress of the United States
House of Representatives

Washington, D.C. 20515

HENRY A. WAXMAN
24TH DISTRICT, CALIFORNIA

COMMITTEES:
INTERSTATE AND FOREIGN
COMMERCE
CHAIRMAN, SUBCOMMITTEE ON
HEALTH AND THE ENVIRONMENT
GOVERNMENT OPERATIONS
DEMOCRATIC STEERING AND
POLICY

BURT MARGOLIN
ADMINISTRATIVE ASSISTANT

SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT
COMMITTEE ON ENERGY AND COMMERCE

DATE: April 13, 1982

TIME: 10:00 a.m.

PLACE: THE GAY AND LESBIAN COMMUNITY SERVICES CENTER
1213 North Highland Avenue
Los Angeles, California

SUBJECT: Hearing on Kaposi's Sarcoma and Opportunistic Infections

WITNESS LIST

- | | |
|--|--|
| 1) Thomas Nylund
Director of Medical Services
The Gay and Lesbian Community
Services Center
1213 North Highland Avenue
Los Angeles, CA | 5) Stan Matek, President
American Public Health Association
1015 - 15th Street, NW
Washington, D.C. 20005 |
| 2) James W. Curran, M.D.
Coordinator of the Task Force
on Kaposi Sarcoma and
Opportunistic Infections
The Centers for Disease Control
Atlanta, GA 30333 | 6) James Lipsett, M.D.
Executive Committee
Southern California Physicians for
Human Rights, and Radiation
Oncologist
City of Hope National Medical Center
Los Angeles, CA |
| 3) Bruce A. Chabner, M.D.
Acting Director
Division of Cancer Treatment
National Cancer Institute
Building 31, Room 3A52
Bethesda, MD 20205 | 7) Michael S. Cottlieb, M.D.
Assistant Professor
Department of Medicine, and Member,
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| 4) Bobbi Campbell, R.N.
500 Hayes Street
San Francisco, CA 94102 | Marcus A. Conant, M.D.
Associate Clinical Professor of Medicine,
and Co-Director
Kaposi Sarcoma Clinic
UCSF Medical Center
San Francisco, CA |

TESTIMONY BEFORE CONGRESSIONAL COMMITTEE ON HEALTH
Congressman Henry A. Waxman, Chairman

Tuesday, April 13, 1982

By: Marcus A. Conant, M.D., Co-Director Kaposi Sarcoma Clinic
University of California Medical Center, San Francisco

Exactly one year ago, in April of 1981, we learned from our colleagues at New York University of an outbreak of Kaposi's sarcoma and pneumocystis pneumonia among male homosexuals in New York City. Within twenty-four hours we had confirmed that there was a case of this malignancy in San Francisco. My colleagues and I at the University of California in San Francisco were already deeply committed to a number of other projects but there were many aspects of this new outbreak that caught our attention and captured our imagination.

First, the disease appeared to be spreading from a point source in New York suggesting either some infectious agent or some common environmental factor.

Kaposi's sarcoma, an extremely rare form of cancer, had previously been seen in Europe among elderly Italians and Jews, and in equatorial Africa among young blacks. This again suggests that the disease may be transmissible and argues that there are certain individuals who are genetically susceptible to acquiring this malignancy.

Kaposi's sarcoma and pneumocystis pneumonia are known to attack individuals whose immune systems are not functioning normally, leading immediately to the question, "what was cutting off the immune system in these homosexual men?"

A virus of the herpes family, cytomegalovirus to be specific, had been implicated as a possible cause of Kaposi's sarcoma in Africa

ten years before, but work in this area had progressed slowly because of political unrest in Uganda. Could a new form of this virus have emerged in this country?

We were therefore presented with a challenging scientific dilemma. What is causing this cancer, why is it occurring at this point in history, and why is it occurring just in the homosexual community? While the answers to these questions are not immediately apparent, even individuals not familiar with the techniques of studying these questions, will immediately sense that with enough study which of course requires enough brain power and enough money, the answers to these questions could be found.

Recognizing the size of the gay community in San Francisco and the unique geographical configuration of our City, my colleagues and I decided to establish a multidisciplinary clinic to study some of the questions that I have just raised. The clinic began as a handful of investigators last summer and has grown progressively to encompass representation from virtually every medical discipline at our University. We have defined for ourselves four tasks.

The first is to teach clinicians on the West Coast to recognize these diseases so that early diagnosis can be made and early treatment can be initiated.

The second is to study the spread of the disease and to bring new research techniques to bear to investigate the factors that have cut off the immune mechanisms of these patients, the viruses that they have acquired and the genetic makeup of each victim.

The third is to treat the patients. A variety of therapies immediately come to mind. Should the patients be treated with

conventional chemotherapy to destroy the cancer; should they be given experimental interferon in an effort to poison the virus; or should they be given new experimental drugs such as Thymazine in an effort to stimulate their lagging immune system? All of these questions are being explored.

The fourth task is to provide emotional support to these unfortunate individuals. To be twenty years old and told that even though you feel well, you have a malignancy that may be fatal, can be a devastating emotional experience. Prompt and compassionate expert psychiatric assistance is needed to help these patients deal with their illness.

Work has progressed rapidly. We now have twenty patients that we are treating and studying. In this short time we have identified two new diseases occurring in this population.

We have found squamous cell carcinoma of the tongue in the lover of one of the patients suffering from Kaposi's sarcoma, suggesting that Kaposi's sarcoma may not be the only malignancy that we will see in these immunosuppressed individuals.

We have identified a new opportunistic infection, Cryptosporidiosis, which was until recently unknown as an infection of man.

We have identified cytomegalovirus in all of these patients and are preparing a paper for publication which shows that the virus appears to be in the cancers.

Work is ongoing in the areas of immunology and genetics in an effort to identify who is at risk and what happens to the patient's immune system.

Cooperation from federal and local agencies has been exemplary.

We were contacted by Dr. Harold Joffe from Dr. Curran's office at the CDC. They have kept us apprised of the findings of the CDC, and we in turn have notified them of new cases and new discoveries. The CDC initiated a contact control study last fall in an effort to identify the factors responsible for this new outbreak. The physicians in San Francisco have worked closely with this federal agency in this endeavor and they have kept us posted of their findings on a regular basis.

Dr. Selma Dritz, the physician epidemiologist of the City of San Francisco, is an active member of our clinic and we work closely together in our efforts to identify cases and teach health care providers to recognize the disease.

The National Cancer Institute, an agency of the federal government, recognized the importance of this problem last summer and sponsored an international meeting in Bethesda in an effort to bring together experts from all over the world and focus their attention on this newly emerging health problem.

The response from the private sector has been equally encouraging. Physicians and scientists at our institution have given freely of their time and resources to study this problem. Since this disease was new and unexpected, no

funds had been earmarked for these studies and all of the work done to date has been on a voluntary basis.

The American Cancer Society stepped forward with a \$50,000 grant last month to furnish us the resources to hire a Nurse Coordinator who is desperately needed to coordinate the examinations, X-rays, investigations and treatment of all of these patients.

The press has been restrained and responsible in reporting the facts of this problem. They have avoided inappropriate sensationalism which could have led to unwarranted fear and panic.

Religious groups have approached us to offer assistance with the emotional needs of the victims and their families.

What is needed from the federal government in the months to come? The answer is simple and straight forward. Money in the form of support for our research and a continued participation of federal agencies.

Sizeable funds in the range of hundreds of thousands of dollars will be needed to study these diseases and answer the questions that I have just posed. The federal government through the National Institutes of Health, is the traditional and indeed only agency capable of financing research of this magnitude and complexity. Private agencies are often willing to help but they have neither the resources to make a meaningful contribution or the expertise to decide which of a variety of proposals has merit and which will probably lead down a blind alley.

And what will all this money buy? If we can answer the questions that I have posed about these new diseases, it will greatly expand our knowledge of the human immune system and of the role of viruses as a cause of cancer. Answers to these

questions should help us understand the immune response to common viral diseases and why some individuals suffer from recurrent yeast infections while others appear immune to this annoyance. If we can understand the role of cytomegalovirus in the production of Kaposi's sarcoma, we may begin to understand how herpes simplex virus is related to cervical cancer in women with recurrent genital herpes.

We have heard that the funds to the CDC may be cut. This would indeed be shortsighted economy. If anything, we should learn from our recent past that our civilization will continue to be visited with plagues and pestilence. In the last ten years we have seen an epidemic of Legionnaire's disease among old veterans, and then toxic shock syndrome among young menstruating women, and now Kaposi's sarcoma among young homosexual men. With each of these epidemics, the CDC has been there to alert the public, to coordinate the studies and to support the scientists in the field. If the federal government thinks that Kaposi's sarcoma is the last plague that we will see, we are naive. If we think that we won't need the CDC when the next one strikes, we are indeed foolhardy.

How should funds for Kaposi's sarcoma and pneumocystis pneumonia be earmarked? I respectfully suggest that the Kaposi's sarcoma task force of the CDC be separately funded and its activities expanded. Further epidemiological information on this disease is urgently needed. This is a national, not a local problem; and the national agency charged with epidemiological surveillance can get us the necessary answers in the quickest and most economical fashion. Congress should direct that a national cooperative study of this problem be funded through the National Cancer Institute. In this way we can husband the tremendous intellectual resources available at teaching hospitals in major cities and avoid unnecessary reduplication of studies. If we do get the money we can begin to answer these questions that I have raised, but I can assure you that if we don't get the money, we can't.

Thank you.