Memorandum

Date June 17, 1981

From Deputy Director
Parasitic Diseases Division
Center for Infectious Diseases

Chief, Research Branch
VD Control Division
Center for Prevention Services

Subject Trip Report - Kaposi's Sarcoma in New York City

To Dr. Robert L. Kaiser
Assistant Director for International Activities
Center for Infectious Diseases

On Thursday afternoon, June 11, 1981, we departed for New York City to 1) firm up information we had received from Dr. Friedman-Kien on Monday, June 8, 1981, 2) determine how many physicians and institutions were involved, 3) identify principal persons who could facilitate a CDC investigation, 4) obtain any data supporting or refuting the hypothesis that there has been a recent increase in the number of Kaposi's Sarcoma (KS) diagnoses, and 5) collect sufficient information to permit drafting of an MMWR article.

Thursday evening we met with Dr. Jack Weissman, Assistant Professor of Medicine, Department of Medicine, Columbia Presbyterian Medical Center, New York. The meeting occurred at 10:30 a.m. and the information obtained was based on Dr. Weissman's recall rather than from individual patient records. Three male homosexual patients had been referred to Dr. Weissman for infectious disease work-up of peripheral lymphadenopathy over the past 18 months. Dr. Weissman's first thought upon seeing the first patient was to rule out TB. Repeated biopsies of lymph nodes over a 6-month period yielded no specific findings. Skin lesions which appeared after the patient's initial visit to Dr. Weissman were subsequently biopsied and pathologically confirmed as KS. The patient was subsequently referred to an oncologist for therapy. The second patient seen by Dr. Weissman also presented with lymphadenopathy, and KS was confirmed by skin biopsy. The third and most recent patient has not yet been pathologically confirmed as KS, but he presented with similar signs, including lymphadenopathy. The third patient is reported to have been the roommate of one of the first two patients. Dr. Weissman was going on vacation Friday afternoon; therefore, no additional details about his patients could be obtained from his files. However, Dr. Weissman did indicate that he would be happy to open his files to an investigative team from CDC and thought his patients would be willing to consent to an interview.

The following morning we had breakfast with Dr. Dan William, a private physician in New York City. Dr. William has diagnosed KS in 3 male homosexuals over a one and one-half year period. Two of the patients presented with skin lesions while the third presented a rectal abscess and inguinal lymphadenopathy. The abscess was drained, but the patient returned because the inguinal lymphadenopathy had not resolved. KS was subsequently diagnosed from a biopsied skin lesion. Dr. William also pledged his cooperation in assisting CDC in further investigations of KS in New York City.

We spent the rest of Friday at New York University Medical Center with Dr. Alvin Friedman-Kien and his staff. During the morning hours we met with Dr. Friedman-Kien, Dr. Anna Ragas, Assistant Professor of Dermatology, New York University; and Dr. Michael Marmor, Research Associate Professor, Laboratory of Biostatistics and Epidemiology, NYU. Dr. Friedman-Kien provided us with a line listing of KS patients, including the name, address, and telephone number of at least one of the physicians who attended these patients. We spent the morning trying to firm up clinical data on patients, i.e., presenting symptoms and signs, clinical course, concurrent illnesses, and outcome.

Dr. Friedman-Kien has established himself as the person who will perform a clearing house function for KS patients diagnosed in New York City. It is not clear at this time whether this self-appointed role is supported by all physicians in New York City handling cases. Dr. Friedman-Kien does seem to have the support of several private practitioners in the community.

On Friday afternoon, we met with other members of the NYU staff involved in patient management and interviewed one patient with KS. In addition to Dr. Curran and myself, the following persons attended the meeting: Drs. Alvin Friedman-Kien, NYU; Anna Ragas, NYU; Elena Klein, Immunologist, NYU; Neil Prose, Dermatology Resident, NYU; Linda J. Laubenstein, Department of Oncology, NYU; Michael Marmor, Epidemiologist, NYU; Franco Muggia, Oncologist, NYU; and Jeffrey Gottleib, Pathologist, Cornell Medical Center. No representatives from Memorial Sloan-Kettering or the New York City Health Department were present. It was clear from our discussions with this group that many of the KS patients have been seen by 3 or more physicians during their work-up. This may present a stumbling block in obtaining detailed information from patients' charts since the investigative team may have to get permission from multiple physicians to access each patient's chart.

Some evidence was provided by Dr. Marmor to suggest that a real increase in the number of KS patients was occurring in New York City. He reviewed the New York State Tumor Registery for the years 1970-1979 and was able to identify only 19 cases in the 20- to 49-year-age group. Six of these persons were single, 7 were married, and the marital status of 6 was unspecified. However, the New York City Tumor Registry did not begin until 1977. Dr. Marmor also reviewed hospital pathology records for KS patients less than 50 years of age. A review of records at Bellevue for the period 1970-1979 revealed no cases. Records at New York University Medical Center were reviewed for the period 1961-1979; 3 cases were identified, a 19-year-old, a 43-year-old, and a 47-year-old.

Duplicate case reporting has been, and may continue to be, a problem. Our current assessment is that there have been 20 KS patients confirmed in New York City. There may be 2 additional New York City patients, but we could not rule out the possibility that they were already included in the 20. In addition to the 20 New York City cases, 8 other cases were clearly .

identified. Six of the 8 occurred in California (3 from Stanford, 2 from San Francisco, and 1 from Salinas). The Salinas patient has moved to Texas and is believed to be hospitalized at the M.D. Anderson Hospital in Houston. One patient has been identified in Miami and 1 in Montreal. All patients identified thus far are male homosexuals and range in age from 25 to 51 years.

The following epidemiologic data pertains only to the 20 New York City cases. Patients ranged in age from 26 to 51 years with a mean age of 39 years. Only 2 patients were in their 20s and 1 was in his 50s. The racial composition of patients is predominantly Caucasian ; 1 black patient has been identified. Ethnic backgrounds of Caucasian patients are variable. Seven of the 20 New York City patients have died; 1 patient is close to dying.

From information pieced together on these patients we got the impression of a disease with a variable clinical picture. The presenting complaint was known in 14 cases: 6 patients presented with skin lesions only; 3 others with skin lesions and lymphadenopathy; and 1 with a perirectal abscess, inguinal adenopathy and a single skin lesion. Four patients presented primarily with constitutional symptoms including weight loss and fever; 2 of these had pneumonia diagnosed at time of presentation (1 caused by _Pneumocystis carinii_). Five of 13 patients for whom information was available had other principal diagnoses in addition to KS. These included 4 with pneumonia (2 due to _Pneumocystis carinii_) and 1 with necrotizing toxoplasmosis of the central nervous system (diagnosed at post-mortem examination). One of the patients with _Pneumocysti_ pneumonia also experienced severe recurrent herpes-virus infection, extensive candidiasis, and cryptococcal meningitis. Nine of 11 patients for whom information was available had a past history of amebiasis. Similarly, 9 of 11 had a history of hepatitis, though the type was not usually specified. Results of tests for cytomegalovirus (CMV) infection were available from 9 patients. Seven of 7 tested for antibody had serologic evidence of CMV infection. CMV was identified in the tumor genome from 1 patient and demonstrated in a stained autopsy specimen (lung) from another patient.

Year of Presentation	Number of Patients	Status
1979	5	2 alive; 3 dead
1980	5	2 alive; 3 dead (1 dying)
1981	3	3 alive
Unknown year	7	(6 alive; 1 dead)
Total	20	13 alive; 7 dead (1 dying)

The median duration of illness from time of presentation for those who died was 15 months (mean 13 months); for patients living the median duration was 10 months (mean 12 months).

We got the feeling that many patients visited multiple doctors before the diagnosis was considered. Repeat biopsies were often performed with equivocal readings. Interpretation of lymph node biopsies appeared to pose the most difficulty. Definitive diagnosis usually required skin or visceral biopsy. After the diagnosis of KS is confirmed, there is often further delay before therapy is initiated. In part, delays in initiating therapy may be due to uncertainties about the natural history of untreated disease and the selection of appropriate chemotherapeutic agents.

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P.S. Since returning to CDC, 4 additional cases have been brought to our attention (2 in San Francisco [both male homosexuals in their 30s] and 2 in Georgia [sexual preference unknown]). One of the Georgia cases came to Atlanta directly from New York City.