Summary Minutes of NIH Kaposi Sarcoma Working Group (KSWG)

(July 20, 1982)

Present: Drs. Heinz Berendes, James Goedert, Robert S. Gordon, Jr. (chair), John Hooks, Arthur Levine, Henry Masur, Walter Miller,* Harold Schoolman, Kenneth Sell (co-chair), and N. Raphael Shulman

Also Present: Dr. Prabhakara V. Choudary, NIMH (auditor)

Absent: Drs. Amoz Chernoff, Michael Luster, David Madden, and Robert Nussenblatt

Agenda attached. After a round of introductions, Dr. Gordon reviewed the charge to the Working Group and its functions. It is not directed to take a pro-active role, nor to usurp the functions of BID's or other PHS agencies in planning and carrying forward studies. It is to facilitate transfer of information among interested workers, and to supplement informal communication in fostering fruitful collaborative relationships. An article is planned for the NIH Record so that all NIH personnel will know that the Working Group has been formed. Any scientist with a possibly useful idea will be encouraged to contact a Working Group member for discussion and/or more information. Dr. Gordon will send one letter to CDC requesting that each member of the Working Group not now receiving MMWR be added to the circulation list.

Dr. Henry Masur then reviewed the ongoing in-patient study in the Clinical Center. Twenty cases have so far been seen that appear to have the syndrome. Eighteen are males, two females; three have died since the study got fully under way three months ago. Samples of blood and other body fluids have been analyzed in a wide variety of laboratories; not all tests are yet completed, nor have results been analyzed. To date, no new putative etiologic agent has been identified.

In discussion, Dr. Sell focussed attention on the possibility of a biohazard problem in laboratories working with samples from these cases. No investigator should undertake studies without attention to containment.

Dr. Goedert then described his and parallel studies designed to uncover latent cases of immunodeficiency among high-risk groups who have no clinical manifestations of illness. His prepared summary is attached.

*For Dr. Chernoff

Finally, there was general discussion of the information about the syndrome that had been presented at meetings in New York on July 13, and at FDA/BOB on July 16. The appearance of the syndrome in three hemophiliacs has given the epidemic a new aspect. The cases strongly suggest parenteral transmission of a viral agent, and cause concern that the population of some 20,000 hemophiliacs in the United States who are dependent on blood products may be at risk. CDC, FDA/BOB, and NIH have been asked by the Assistant Secretary for Health to provide recommendations for steps that might feasibly be taken to limit this risk, and a meeting to consider the problem is to be held at the Humphrey Building on Tuesday, July 27. Several members of the Working Group have been invited to participate.

Before adjournment, Dr. Gordon indicated that there is no future meeting planned at this time, but one will probably be called in September, after vacation season is over. In the interim, a special ad hoc meeting may be called if an issue arises.

Submitted by,

R Gordon

Robert S. Gordon, Jr., M.D.
Special Assistant to the Director, NIH
Chairman, NIH KSWG

cc: With attachments

KSWG Members
Dr. James Curran, CDC

Without attachments

OD Staff
BID Directors
Scientific Directors