

**PHOTOCOPY
PRESERVATION**

THE WHITE HOUSE

Eric —

11/18

Neel Lane mentioned that to
you at the senior staff mtg. This morning,
and asked that we send you a copy
ASAP. We expect to have written
confirmation later today that PM Blair
does indeed approve of a joint statement.

Tell Smith 6-6047

THE WHITE HOUSE
WASHINGTON

November 17, 1999

HEALTH -
GENOME
PROJECT

ACTION

MEMORANDUM FOR JOHN PODESTA

FROM: NEAL LANE *for JH*

SUBJECT: POSSIBLE JOINT U.S.-U.K. STATEMENT ON THE HUMAN
GENOME PROJECT

Background

Almost one year ago, Harold Varmus reported to me that Prime Minister Tony Blair was interested in issuing some form of joint government-to-government statement on the human genome project. The statement (draft attached) has evolved into an endorsement of the policy of making human genome sequence data freely available within 24 hours of its generation. This practice is now a requirement for recipients of funds from the three principal not-for-profit partners in the international Human Genome Project: the NIH, DOE and U.K.'s Wellcome Trust. I have had a number of discussions about the merits of issuing a high-level statement with my U.K. government colleagues, Lord Sainsbury, Minister for Science, and Sir Robert May, Chief Scientific Advisor to the Prime Minister, as well as with Dr. Michael Morgan, CEO of the Wellcome Trust's Genome Campus. All three support such a statement and Morgan reports today that the Prime Minister has just given his approval.

The draft statement made the news on September 20th with an article in the London Guardian that was largely inaccurate in portraying it as a means for preventing entrepreneurs from obtaining patents (article and our press guidance are attached). It is true that public deposit renders information unpatentable. However, the statement is carefully worded to endorse free access to "fundamental data on the human genome, including the human DNA sequence and its variations," and does not criticize subsequent intellectual property claims to protect discoveries based on such sequences. Thus, the statement has limited relationship to patenting genome-based products. Issuing the statement might be useful in addressing the persistent confusion left by the Guardian article.

Next Tuesday, November 23rd, the Human Genome Project international partners will hold a multi-site event to mark the sequencing of the billionth DNA base pair (roughly one-third of the entire human genome). DHHS submitted a POTUS scheduling request with the hope of announcing the joint statement, in addition to another initiative that is not completed, but that we might discuss at a later date. Participants across the U.S. and the Sanger Centre in Cambridge, U.K., will be linked via satellite. Secretary Richardson's attendance is confirmed, and Secretary Shalala may also attend. Their roles will be to extol the virtues of the genome project, but they will not address the joint statement. Lord Sainsbury is prepared to represent the Prime Minister

on the U.K. side to announce his approval of the joint statement, if the President agrees to do the same. If so, I can be available to speak on his behalf next Tuesday at the National Academy of Sciences, the local event site.

Decision on issuing a joint U.S.-U.K. statement:

☐ Yes ☐ No ☐ Let's discuss

Possible Action:

The President and Prime Minister Blair will meet informally in Florence on Saturday. Perhaps they could discuss this issue briefly and agree to a coordinated announcement of the joint statement on Tuesday, November 23.

Attachment

cc: Bruce Reed
Sandy Berger
Thurgood Marshall, Jr.
Leon Fuerth
David Beier
Chris Jennings

DRAFT

**JOINT STATEMENT TO ENSURE THAT
DISCOVERIES FROM THE HUMAN GENOME PROJECT
ARE USED TO ADVANCE HUMAN HEALTH**

In the last decade of the twentieth century, scientists from around the world initiated one of the most significant scientific projects of all time: to determine the DNA sequence of the entire human genome, the human genetic blueprint. Progressing ahead of schedule, human genome research is rapidly advancing our understanding of the causes of human disease and will serve as the foundation for development of a new generation of effective treatments, preventions, and cures. To realize this promise, fundamental data on the human genome, including the human DNA sequence and its variations, must be made freely and broadly accessible to scientists everywhere. The human genome is the fundamental shared heritage of all humankind. Unencumbered access to this information is essential to enable discoveries that will reduce the burden of disease and promote health around the world. We applaud the decision by scientists working on the Human Genome Project to release information about the human DNA sequence and its variants rapidly into the public domain, and we call on all scientists worldwide to adopt this policy.