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18 September 1989

The Honorable D. Allan Bromley
Director
Office of Science and Technology Policy
Executive Office of the President
Washington, DC 20506

Dear Dr. Bromley,

I wish to bring to your attention some actions taken by OSTP on US-Japan cooperation on genome projects before your tenure as Director. I am writing as former director of the Office of Technology Assessment (OTA) report on genome projects, a copy of which is enclosed.

The issue of US-Japan cooperation on genome projects is timely for several reasons. First, the US effort has begun to take shape, and agencies (particularly NIH and DOE, but also NSF and USDA) have moved from concept to serious planning and implementation. The need for structured international collaboration has become clear, particularly for databases (of DNA sequence, chromosomal map, and other data) and repositories (for DNA clones, probes, cell lines, and other materials). Second, an international scientific organization, the Human Genome Organization (HUGO), has formed but is not yet fully operating. Third, the Soviet, Italian, and Australian governments have made commitments to fund HUGO, and there are serious discussions going on with government and private organizations in the United States, United Kingdom, and Canada. To date, the Japanese government and private interests in Japan have not made any commitments to HUGO. Fourth, the Japanese government has had several procedures in place to set policy on genome projects, to determine the nature and number of resources it should devote to genome projects.

I am writing you because OSTP inadvertently complicated the situation. Genome projects were listed by the Japanese as possible areas of cooperation at an April meeting on the US-Japan agreement on science and technology. At that meeting, Janet Dorigan from OSTP is reported to have said that the US did not plan to include genome projects in the cooperative agreement. I do not know exactly what she said, and she does not recall either. But the Japanese government, or at least part of it, has taken this as an indication that the US government does not plan to cooperate on genome projects in general. This came to my attention on August 29, when I received a facsimile message from Akihiro Yoshikawa, of the University of California at Berkeley Department of Economics, who was in Japan for other business and kindly agreed to discuss the genome project with selected scientists and government officials at my request. (He wrote the Japan background paper for OTA's genome project, and has since remained interested.) I have since spoken with Janet Dorigan, Sara Bowden, Mary Ann Murray, and several others who were in critical positions, in an attempt to find out how the policy was formulated and what was actually said. There is, unfortunately, little in the way of documentation, other than an indication that the Japanese did have genome projects listed specifically for discussion, and the US did not. The Japanese apparently have extensive notes, and perhaps a translation of their notes could be requested.

The timing of the US-Japan discussion complicated internal planning on genome projects in Japan, both within and among agencies (the Science and Technology Agency, the Ministry of Education, the Ministry of Health and Welfare, and the Ministry of International Trade and Industry). Just in March, the Science and Technology Agency had released the report of a scientific council that set forth a multicomponent genome research effort, and the final negotiations were taking place for annual science budgets. Some memos from the Ministry of Education that recent came to my attention also suggest that its planning process was poised for action in early Spring, yet no action has

been taken. The US statement may have contributed to scuttling these one and one-half year Japanese planning efforts.

Japan has a small but growing human genetics capability. Its proportion of publications in this field increased from 2 percent in 1977 to 5 percent in 1986 (compared to 45 percent and 43 percent, respectively, for the United States). In future years, as genome projects progress, Japanese scientists will doubtless play an even larger role if their government makes a substantial commitment. The US-Japan discussions in April, coupled with the recent instability of leadership in the Japanese government, have apparently put this commitment in jeopardy. Government officials seem to be using the US statement as an indication that the scientific priority of the human genome project is low, and as an argument against substantially increased funding in Japan.

Genome projects are likely to proceed, at one level or another, for several decades. The data from chromosomal mapping and DNA sequencing are extremely important to share throughout the world, and mechanisms to ensure such sharing have just begun to work (e.g., international agreements among the three principal DNA sequence databases in the United States, Europe, and Japan). For the United States to refuse an offer of cooperation at this juncture could seriously damage both US credibility (the OSTP position could easily be interpreted to contradict many US statements about genome projects issued by NIH, DOE, OTA, and the National Academy of Sciences, for example) and could threaten current and future international scientific agreements in molecular biology.

Genome projects are first and foremost intended to generate a tool for biomedical research. That tool is chromosomal map and DNA sequence information. Creation and storage of human genetic information present natural opportunities for international scientific cooperation. The genome can only be mapped and sequenced once, and this underlies some of the excitement about genome projects in the scientific community. Such data clearly should not be proprietary. This principle is agreed upon by all US interests (including the National Research Council, OTA, NIH, DOE, and the Industrial Biotechnology Association), in Japanese statements (both formal and unofficial), and in international statements (by UNESCO and HUGO). The principal use of this information will be to eradicate human diseases throughout the world. The United States has a great deal to gain, and very little to lose, by supporting data sharing among all nations.

There are parts of genome projects for which international cooperation will be difficult because of international technological competition and forces of economic nationalism (e.g., development of DNA sequencing instruments). But these areas can be separated from the much more important need to share basic scientific data. It is certainly true that for many years US scientists will continue to put more information into databases than Japanese scientists, but barring a loss of support the contribution from Japan will undoubtedly continue the increase shown over the past decade. It could only weaken the databases to exclude map and sequence data from Japan, and similar data from other nations with rapidly increasing science programs likely to use Japan as a database "node" (e.g., Korea, Thailand, Taiwan, and the People's Republic of China). It is also in the long-term interests of the US government to support Japanese scientists in augmenting their molecular biology science base, so that Japan can eventually begin to support biomedical research in proportion to the size of its economy.

It may well the the case that the US-Japan Science and Technology Agreement is not the appropriate vehicle for genome research cooperation. Bilateral agreements can become inflexible and bureaucratically intractable, and tend to involve political considerations well beyond the confines of science. It does seem, however, that a clarification of the US position on US-Japan cooperation on genome projects may be in order, particularly as regards databases, materials repositories, and joint support of HUGO. I urge you to consider placing a discussion of areas for cooperation on the agenda for discussion with your counterparts in Japan.

Thank you.

Sincerely,

Robert Mullan Cook-Deegan, M.D.
Acting Executive Director

cc: James Wyngaarden
John H. Gibbons

Encl: OTA report: Mapping Our Genes – Genome Projects: How Big? How Fast?