



DEPARTMENT OF HEALTH & HUMAN SERVICES

National Institutes of Health
National Human Genome Research Institute
FOIA/PA Office, RKL 1, Suite 6054
6705 Rockledge Dr, MSC 7957
Bethesda MD 20892-7957

May 22, 2012

Robert Cook-Deegan, M.D.
Duke University
Institute for Genome Sciences & Policy
Durham, NC 27708

Re: FOIA Case Number: 12-FOI-00224-NHGRI – 39937

Dear Dr. Cook-Deegan:

This is our final response to your April 13, 2012, Freedom of Information Act (FOIA) request addressed to the National Human Genome Research Institute (NHGRI), National Institutes of Health (NIH). You requested information on the International Strategy Meetings for Human Genome Sequencing including: 1) any handwritten notes taken by Dr. Francis Collins (then Director of NHGRI), at the Second (1997) and Third (1998) International Strategy Meetings for Human Genome Sequencing in Bermuda, 2) the official agenda for the Second International Strategy Meeting (1997), 3) any official reports resulting from any of the three International Strategy Meetings for Human Genome Sequencing (1996, 1997, 1998), and 4) any letters sent by NCHGR/NHGRI from 1996 to 1998 to foreign dignitaries, scientists, administrators, or policymakers relating to compliance with the rapid DNA data release policies of the International Human Genome Project. In an email exchange on May 21, you agreed to exclude the 1997 official report.

We searched the files of the NHGRI Office of the Director for records responsive to your request. That search produced 107 pages responsive to your request. In response to item 1, enclosed are handwritten notes from the 1997 International Strategy Meetings for Human Genome Sequencing (36 pages), and the 1998 International Strategy Meetings for Human Genome Sequencing (23 pages). In response to item 2, enclosed is the official agenda for the 1997 Second International Strategy Meeting (13 pages). In response to item 3, enclosed is the official report from the 1996 International Strategy Meeting for Human Genome Sequencing (5 pages), and the 1998 International Strategy Meeting for Human Genome Sequencing (26 pages). In response to item 4, enclosed are letters sent by NCHGR/NHGRI from 1996 to 1998 to foreign dignitaries, scientists, administrators, or policymakers relating to compliance with the rapid DNA data release policies of the International Human Genome Project (4 pages). A total of 107 pages are being released in response to this request.

In certain circumstances provisions of the FOIA and Department of Health and Human Services FOIA Regulations allow us to recover part of the cost of responding to your request. Because the cost is below the \$25 minimum, there is no charge for the enclosed materials.

Thank you for your interest in the National Human Genome Research Institute.

Sincerely,

Christy Cecil
Freedom of Information Specialist, NHGRI

Enclosures – 107 pages



DEPARTMENT OF HEALTH & HUMAN SERVICES

National Institutes of Health
National Human Genome Research Institute
FOIA/PA Office, RKL 1, Suite 6054
6705 Rockledge Dr. MSC 7957
Bethesda MD 20892-7957

April 16, 2012

Robert Cook-Deegan, M.D.
Duke University
Institute for Genome Sciences & Policy
Durham, NC 27708

Re: FOIA CASE NO. 12-FOI-00224-NHGRI – 39937

Dear Dr. Cook-Deegan:

This acknowledges your April 13, 2012, Freedom of Information Act (FOIA) request addressed to the National Human Genome Research Institute (NHGRI), National Institutes of Health (NIH). You requested information on the International Strategy Meetings for Human Genome Sequencing in 1997 and 1998, including: (1) handwritten notes taken by Dr. Francis Collins, then Director of NHGRI, at the Second (1997) and Third (1998) International Strategy Meetings for Human Genome Sequencing in Bermuda, (2) the official agenda for the Second International Strategy Meeting (1997), (3) any official reports resulting from any of the three (1996-1998) International Strategy Meetings for Human Genome Sequencing, and (4) any letters sent by NCHGR/NHGRI (or NIH) from 1996-1998 to foreign dignitaries, scientists, administrators, or policymakers relating to compliance with the rapid DNA data release policies of the International Human Genome Project, particularly letters sent to individuals from France, Germany, and Japan.

We have queried the NHGRI Office of the Director. If any documents responsive to your request are located, they will be reviewed for releasability, and all releasable information will be sent to you. We will do everything possible to comply with your request in a timely manner. Please feel free to call me at 301-496-9737 for additional information or to inquire about the status of your request.

Provisions of the FOIA allow us to recover part of the cost of complying with your request. We shall charge you for records in accordance with the Department of Health and Human Services FOIA regulations as they apply to educational institution requesters; i.e., you will be charged for duplication at 10-cents per page although the first 100 pages are free; there is no charge for search or review time. If there are any fees associated with processing this request, you will be sent an invoice with our final response.

Sincerely,

A handwritten signature in cursive script that reads "Christy Cecil".

Christy Cecil
Freedom of Information Specialist, NHGRI



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

National Institutes of Health
National Human Genome
Research Institute
31 Center Drive MSC 2152
Building 31, Room 4B09
Bethesda, MD 20892-2152
(301) 496-0844
Fax (301) 402-0837

March 9, 1998

351 8883 383

3-10-98 to A. Patrinos

Professor Kenichi Matsubara
Institute for Molecular and Cellular Biology
Osaka University
1-3, Yamada-oka, Suita
Osaka, 565
Japan

FILE COPY

Dear Professor Matsubara:

At the recent International Strategy Meeting on Human Genome Sequencing (Bermuda, February 27-28, 1998) a discussion was held about current worldwide practices in DNA sequence data release. As you know, one of the conclusions of the first Bermuda conference in 1996 was that all human genomic sequence produced by large scale sequencing centers should be placed in the public domain as soon as contigs of 1-2 kb have been generated, and larger, assembled contigs should also be made publicly available as soon as they are generated.

The attendees at this year's meeting reconfirmed their strong belief in this policy, and in fact voted unanimously that this rapid data release standard should now be extended to large scale DNA sequencing of all organisms.

Professor Yoshiyuki Sakaki of the University of Tokyo, Mr. Fumihiko Kikuchi of JST, and Dr. Asao Fujiyama of the National Institute of Genetics attended this year's meeting for Japan. We understand from their presentations that there are currently four Japanese groups funded to do large scale genome research. Two significant concerns were raised about data release, however. First, only Professor Sakaki appears to be adhering to the policy of rapid release of unfinished DNA sequence contigs of 2 kb or more; the other

three centers apparently do not do this. Second, it seems that JST still insists on reviewing completed sequence contigs (which are sent to them every three months) for an undefined period of time before permitting their deposit into the international DDBJ database. Thus, completed sequence contigs may often be inaccessible for many months. We have been unsuccessful in our efforts to learn the reasons for the JST review of the data.

As representatives of three major funding agencies involved in the human genome project, we would like to take this opportunity to urge you to use your influence in the Japanese scientific and government communities to encourage large scale Japanese genome research to come into compliance with current international guidelines. We understand that the JST plan is being reconsidered over the next few months. This would thus seem to be an opportune time to revise the current policy.

The value of large scale DNA sequence data is transforming biomedical research. Yet the realization of that value can only occur with unfettered access by the entire world community. It would be unfortunate if the current situation of less than complete compliance were to be perpetuated in Japan, as the consequences for international cooperation and good will in this noble enterprise might well be significant.

Thank you for your consideration of this letter. You are most welcome to contact any of us for further discussion.

Sincerely yours,



Francis S. Collins, M.D., Ph.D.
Director
National Human Genome Research Institute

Ari Patrinos, Ph.D.
Associate Director for Biological &
Environmental Research
U.S. Department of Energy

Michael Morgan, Ph.D.
Programme Director,
The Wellcome Trust

FSC/phf