



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

SECRET
FEDERAL BUREAU OF INVESTIGATION
UNITED STATES DEPARTMENT OF JUSTICE
WASHINGTON, D. C. 20535

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National Human Genome
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31 Center Drive MSC 2152
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(301) 496-0844
FAX (301) 402-0837

March 21, 1997

FILE COPY

Dr. Frank Laplace
Federal Ministry for Research & Technology
Heinemannstrasse 2
D-53175 Bonn
Germany

Dear Dr. Laplace:

At the Second International Strategy Meeting on Large-Scale DNA Sequencing, held February 28 - March 1, 1997 in Bermuda, attendees reaffirmed how critical it is to the integrity and success of the international Human Genome Project that human genomic sequence data be rapidly released, without prior exclusive access to it on the part of anyone. We are writing to confirm that the National Human Genome Research Institute and the Human Genome Program of the Department of Energy agree with this principle and consider it to be critical to continued support for the Project in the United States. Accordingly, the NHGRI and the DOE have adopted policies to implement appropriate rapid data release practices for all of the large-scale human DNA sequencing projects we are supporting.

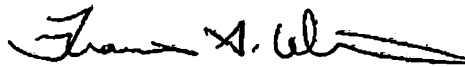
In our view, the key purpose of the rapid release policy is to ensure that the small number of laboratories (funded by public and private charitable sources) that have emerged with the capability to generate large amounts of human DNA sequence data do not take unfair advantage of that capability to gain privileged access to potentially valuable information. The human DNA sequence is a scientific resource of unprecedented importance to all of humanity. By studying it and coming to understand it in much greater depth than we do now, the human DNA sequence will be the basis of many discoveries and developments that will improve human health through new therapeutic and preventative approaches. We enthusiastically support the roles that the biotechnology and pharmaceutical industries will play in realizing the promise of human

genomics through the development of new and important products. However, we also believe that the unusually large amounts of funding for DNA sequencing from both public and private charitable sources was motivated by a desire to make the sequence publicly available. We do not think it is appropriate for selected groups to gain a competitive advantage simply by virtue of having privileged access to the data.

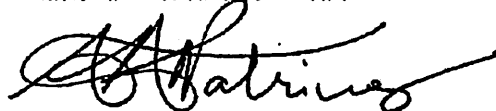
For this reason, we are disturbed that the policy of the German Human Genome Program and the BMBF, as we understand from its description at the International Strategy Meeting, allows German industry restricted access to the prefinished sequence data for a three month period before the finished data are released to the public nucleotide sequence databases. We are convinced that the support enjoyed by the Human Genome Project in the United States, and elsewhere in the world, is predicated on the assumption that no one will have access to the sequence until it is publicly released for all to work with. We are concerned that the BMBF decision to limit access to the sequence produced by the German Genome Program may lead to erosion of that support and potentially to subsequent calls for protection of the sequence produced in this country, and perhaps elsewhere.

It is essential that all of the participants in the international Human Genome Program have the same policy with regard to the release of human DNA sequence data. We urge the BMBF to reconsider its decision and bring its policies into line with those of the other participants. At the International Strategy Meeting, it was argued that the privileged access of German industry to the sequence data produced in Germany was required in order to make German participation in the Human Genome Program possible. It is our opinion that, by definition, continuation of such restrictions on the immediate availability of the sequence data would mean that the German program is not, in fact, participating in the Human Genome Project as it is defined and practiced in the rest of the world.

Sincerely yours,



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



Aristedes A. N. Patrinos, Ph.D.
Associate Director
Office of Health and Environmental Research
Department of Energy

FSC/phf