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

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
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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,

Christy Cecil

Christy Cecil
Freedom of Information Specialist, NHGRI

Report of the International Strategy Meeting on Human Genome Sequencing held at the Princess Hotel, Southampton, Bermuda, on 25th-28th February 1996

Aims of the Meeting

To discuss mechanisms to co-ordinate, compare and evaluate different strategies for human genome mapping and sequencing.

To consider the potential role of new technologies in sequencing and informatics and to discuss different scenarios for data release.

Summary

The following principles were endorsed by all participants. These included officers from, and scientists supported by, the Wellcome Trust, the UK Medical Research Council, the NIH NCHGR (National Institute of Health, National Center for Human Genome Research, the DOE (U.S. Department of Energy), the German human Genome Programme, the European Commission, HUGO (Human Genome Organisation) and the Human Genome Project of Japan. It was noted that some centres may find it difficult to implement these principles because of legal constraints and it was, therefore, important that funding agencies were urged to foster these policies.

Primary genomic sequence should be in the public domain.

It was agreed that all human genomic sequence information, generated by centres for large-scale human sequencing, should be freely available and in the public domain in order to encourage further research and development and to maximise its benefit to society.

Primary genomic sequence should be rapidly released.

- Sequence assemblies should be released as soon as possible; in some centres, assemblies of greater than 1 kb would be released automatically on a daily basis.
- Finished annotated sequence should be submitted immediately to the public databases.

It was agreed that these principles should apply to all human genomic sequence generated by large-scale sequencing centres, funded for the public good, in order to prevent such centres establishing a privileged position in the exploitation and control of human sequence information.

Co-ordination

In order to promote co-ordination of activities, it was agreed that large-scale sequencing centres should inform HUGO of their intention to sequence particular regions of the genome. HUGO would present this information on their World Wide Web page and direct users to the Web pages of individual centres for more detailed information regarding the status of sequencing in specific regions. This mechanism should enable centres to declare their intentions in a general framework whilst also allowing more detailed interrogation at the local level.

To: Collins, fc23a @ nih.gov>" <fc23a@nih.gov (Francis) @ INTERNET
cc: (bcc: Francis Collins/DIR/NCHGR)
From: GuyerM @ odder.nchgr.nih.gov ("Guyer, Mark") @ INTERNET
Date: 03/12/96 04:07:00 PM
Subject: Bermuda report

Here's the summary that we gave to the staff:

Summary of program staff meeting -- 2/29/96

Report on the International Strategy Meeting on Human Genome Sequencing

Mark and Jane both have copies of the full agenda and attendance list, if anyone wants to see them. The major groups that were represented were: Sulston, Waterston, Lander, Myers, Venter, Ansorge, Carrano, Moyzis, Evans, Caskey, Chen, Gibbs, Hood, Lehrach, Rosenthal, Weissenbach, McCombie, Roe, Weber, Hattori, Simon, de Jong, as well as Lipman, Fields, Ashburner. There was more than one person from several of the groups, a total of 50 people altogether, including agency types from Wellcome, NCHGR, DOE, MRC, Germany, Japan, and HUGO.

The major topics discussed were:

the sequencing plans/strategies/accomplishments of each of the groups;
the sequencing resources each group has and will make available (a list of these should have been distributed to staff);
data release;
data quality;
coordination among large sequencing groups.

Some of the key conclusions were:

most sequencing groups seem to be converging on a general strategy of using BACs selected by STS screening and a combination of shotgun and directed sequencing strategies; other strategies, including BAC end sequencing across the genome, shotgun sequencing of the entire genome, and sample sequencing across a complete chromosome were discussed, but in none of these cases was there group consensus that the strategy was superior to the generally-accepted paradigm;

data should be released regularly and very quickly from large-scale sequencing
projects, perhaps as frequently as daily but maybe weekly would do; this refers to preliminary data (i.e. contigs > 1 kb, not finished to database

submission quality) which would be put up locally automatically; it was also agreed that finished, annotated sequence would be immediately submitted to databases;

the attendees unanimously agreed to the following statement: for primary genomic sequence data from large-scale sequencing projects, the aim is to have all sequence freely available and in the public domain for both research and development, in order to maximize its benefit to society. This was intended to mean that the primary producers of the sequence from the Human Genome Project would not attempt to patent the sequence they generate. This statement was understood to be the sense of the attendees and that different organizations/agencies/countries might be under different constraints that might or might not allow them to adopt this as policy. The agencies were, however, urged to foster such policies.

data quality issues -- representation of data quality is becoming possible and
should be reported along with sequence data, particularly in the case of preliminary sequence; the group seemed to be moving toward agreement that the goal is 99.99% accuracy

International Coordination:

As a first step, each of the groups present discussed its goals for the next few years:

Seattle: 25-30 Mb in the next 3 years; primarily centered around the T cell alpha and delta regions on chromosome 7; also the human and mouse MHC regions

TIGR/Cal Tech: 30 Mb in 3 years on chromosome 16p

German consortium (administered by A. Rosenthal at Jena): 30 Mb of chromosome 21 (excluding the minimal Downs and PME regions); 1-2 megabase regions of X (Xq28, Xp11.2, the PAR1 region), 7, 11, 17

LANL: Moyzis original statement was that he intended to do one-pass sequencing across all of chromosome 16; by the time the meeting ended, he was reconsidering that and discussed producing finished sequence of regions of chromosome 16p not being pursued by Sanger or TIGR (a total of about 20 Mb) plus a region near the 5p telomere around the Cri du Chat locus

Whitehead: 105 Mb in 3 yr; human chromosome 17 and mouse syntenic regions plus a few random megabases here and there

Baylor: 30 Mb in 3 yr in Xq28, Xp22, 12p1.3

Oklahoma: I am funded to do 6 Mb in 3 years ; working on the region of 22q between NF2 and the centromere; this is being coordinated with Sanger and Wash U.

Japan: did not say, will report by correspondance after the meeting

Chen/ABD: 4 Mb in various regions on X (this is being coordinated through the X chromosome workshops)

LLNL: 50 Mb in 3-5 years on chromosome 19 and mouse syntenic regions

Wash U: 100 Mb in 3 years; regions on chromosomes 7, 22, and X to begin with

CSHL: 5 Mb from chromosomes 13 and 18

EMBL (Ansorge): cDNAs from chromosomes 21 and X (a total of 2 Mb)

Sanger: 150 Mb in 3 years (actually funded for 7 years to do 250 Mb); beginning with 22 and regions of X, then have all of 6 and 20 targeted, followed by chromosome 1

Marshfield: whole genomic shotgun sequencing will be pursued, hoping for a level of 2-4 Mb (raw?) per year

Dallas: 11p15.5, 11p12, 11q23 (2 mb in each region in 2 years); also pursuing sample sequencing across the whole chromosome.

Agencies: Each of the agencies made a short presentation about its plans. The gist of the information discussed was that the major funders for production human DNA sequencing will be NCHGR and the Wellcome Trust. There is a possibility that DOE and the German genome program will make some significant contributions. There was a brief allusion to developing French plans that could not be discussed in public at present. The European Union and the U.K. MRC will not be spending significant amounts of money on production sequencing. And the Japanese were silent.

There was general agreement that this had been quite a useful meeting and that it would be worthwhile reconvening (perhaps a smaller group) about a year from now.