

PLEASE FILL OUT AND RETURN THIS FORM TO: Center for Public Genomics, Duke University; c/o Susan Brooks; Center for Genome Ethics, Law, and Policy; 304 Research Drive, Box 90141; Durham, NC, 27708. OR: You may fax it to us at (U.S.) 1-919-668-0799.

**Interviewee Information.** Please list an address where we can contact you.

Full name: Aristides A.N. Patrinos Date of interview: 9-1-2011  
Current institutional affiliation: Synthetic Genomics Inc.  
Street Address: 11149 North Torrey Pines Road  
Phone: 858-754-2902 Email address: apatrinos@syntheticgenomics.com

**Interviewer Information.**

Full name(s): \_\_\_\_\_  
Affiliations(s): \_\_\_\_\_

I, the undersigned, have read the above, and I **AGREE** to release my interview materials, subject to any restrictions listed below:

(A)  I place **no restrictions** on my interview materials.

**OR**

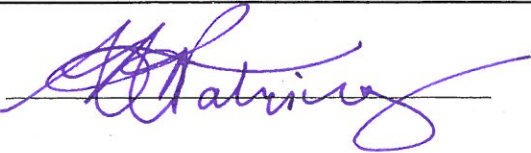
(B)  My interview materials may be reviewed, used, and quoted by the researchers affiliated with the Center for Public Genomics, Duke University; *and in addition* (check all that apply):

- Researchers unaffiliated with the Center for Public Genomics may **read** the interview transcript and any related documents only after obtaining my permission.
- Researchers unaffiliated with the Center for Public Genomics may **quote** from the interview only after obtaining my permission.
- Researchers unaffiliated with the Center for Public Genomics **DO NOT HAVE** my permission to **read or quote** from the interview.

Posting interview materials to public digital archives: In spite of any restrictions listed above, I give permission for my interview materials to be made publicly available on the Internet by deposit in an institutionally affiliated archive:

- 1 year from the date of this form
- 5 years from the date of this form
- 10 years from the date of this form
- 25 years from the date of this form
- After my death
- Other: 3 YEARS (please specify a date or condition)
- NEVER: MAY NOT BE DEPOSITED IN A PUBLIC ARCHIVE

Please specify any further restrictions in the space below:  
\_\_\_\_\_

Signature: 

Date: 10-19-2011

**Informed consent for: “The ethos and effects of data-sharing rules: Examining the history of the ‘Bermuda principles’ and their effects on 21<sup>st</sup> century science”**

**University of Adelaide  
Duke University**

Researchers at the University of Adelaide, Australia, and the IGSP Center for Genome Ethics, Law & Policy, Duke University, are engaged in research on the **Bermuda Principles** for sharing DNA sequence data from high-volume sequencing centers. You have been selected for an interview because we believe that the recollections you may have of your experiences with the International Strategy Meetings for Human Genome Sequencing (1996-1998) will be interesting and helpful for our project.

We expect that interviews will last from 30 minutes to much longer, but you may stop your interview at any time. Your participation is strictly voluntary, and you do not have to answer every question asked.

Your interview is being recorded and we may take written notes during the interview. After your interview, we may prepare a typed transcript of the interview. If we prepare a transcript, you will have an opportunity to review it and to make deletions and corrections.

Unless you indicate otherwise, the *information* that you provide in this interview will be “on the record”—that is, it can be attributed to you in the various articles and chapters that we plan to write, and thus could become public through these channels. If, however, at some point in the interview you want to provide us with information that might be useful for us to know, but which you do not want to have attributed to you, you should tell us that you wish to go “off the record” and we will stop the recording. We will, however, take notes for our own use. When you are ready to go back “on the record,” we will resume recording. Anything you say while “off the record” will not be on the audio recording and therefore will not appear in the transcript.

All *materials* from your interview (audio recording; transcript; interviewer's notes) will be available only to members of the research team affiliated with this project, unless you consent to their wider use, as described in the paragraph below. The digital materials will be maintained in a secure, HIPPA-compliant drive at Duke University. The paper materials will be stored in a locked cabinet.

In addition to the scholarly articles and chapters that we plan to write, we also hope to create a resource for other scholars and members of the public. We plan to post some of our research data to online digital archives. While we will use your “on the record” comments to inform and write our articles, we will not post your interview transcript or audio recording online unless you give us permission to do so, in a separate agreement. At the time we send your transcript to you for review, we will also provide a consent form asking your permission to post your interview transcript and/or audio recording online. The form will provide you with different options for how, when, and with whom the materials may be shared. You will, of course, also have the option not to share the materials beyond the Duke and Adelaide researchers.


One risk of this study is that you may voluntarily disclose identifiable information that later could be requested for legal proceedings, or otherwise be used against you. Please take this into consideration when you are speaking. There may be other risks associated with your “on the record” views being made publicly available, such as having your views mischaracterized or misunderstood.

The main benefit of participating in this study is ensuring that your side of the story is properly portrayed in this history of the Bermuda Principles, which have become a model for open and collaborative research in genomics and other fields.

To help us protect the privacy of those parts of your interview that are not public, we have obtained a Certificate of Confidentiality from the U.S. National Institutes of Health. With this Certificate, we investigators cannot be forced to disclose information that may identify you, even by a court subpoena, in any U.S. federal, state, or local civil, criminal, administrative, legislative, or other proceedings. We researchers can use the Certificate to resist any demands for information that would identify you.

The Certificate cannot be used, however, to resist a demand for information from personnel of the United States Government that is used for auditing or evaluation of federally funded projects or for information that must be disclosed in order to meet the requirements of the federal Food and Drug Administration (FDA).

A Certificate of Confidentiality does not prevent you or a member of your family from voluntarily releasing information about yourself or your involvement in this research. If an insurer, employer, or other person or institution obtains your written consent to receive research information, the researchers may not use the Certificate to withhold that information.

Signature  \_\_\_\_\_

Printed Name Aristides Patrinos \_\_\_\_\_

Date Aug 31, 2011 \_\_\_\_\_

*If you have read this form in its entirety and agree to the interview and its terms, please sign and date above.*

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Contact information:

**Rachel Ankeny, Ph.D. (University of Adelaide)**

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**Robert Cook-Deegan, MD (Duke University)**

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*If you have any questions about your rights as a research subject, you may contact the **Duke University Institutional Review Board** at 919-684-3030 or [ors-info@duke.edu](mailto:ors-info@duke.edu).*



THE WELLCOME TRUST

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ref:js/so'd/invite

30th January 1997

Dr Ari Patrinos  
Health Effects & Life Sciences Research Division  
US Department of Energy  
ER-72 GTN  
Washington DC 20585  
USA

Dear Dr Patrinos

The Wellcome Trust along with the National Institutes of Health and the Department of Energy are convening a second International Strategy meeting on Human Genome Sequencing to be held at the Hamilton Princess Hotel, Bermuda from 27th February - 2nd March 1997. The aim of the meeting as before is to facilitate the co-ordination of research groups funded for large-scale human genome sequencing.

I am writing on behalf of Dr Michael Morgan who met Marvin Frazier at Hilton Heads Island who suggested that Dr Morgan invited you and/or Dr Frazier to attend this meeting. We will obviously be delighted if you can attend, but would equally be delighted to see you both. The meeting will be limited to a maximum of 45 participants. The cost of your accommodation and subsistence for the duration of the meeting will be met by the meeting sponsors. However, it is anticipated that participants will be able to meet their own travel expenses.

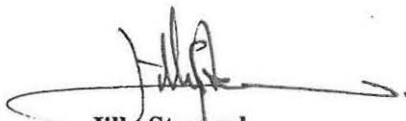
Participants should aim to arrive on the Thursday evening and arrange their return flights on the Sunday morning.

I hope that you and/or Dr Frazier will be able to join us for this meeting which, I am sure, will continue the traditions established last year and provide international collaboration and co-ordination in this vital field of research.

Further details will be sent to you in the near future, but I should be grateful if you could e-mail me your reply by return and no later than **Monday 3rd February 1997** and let me know at that stage whether your departure will be Saturday evening or Sunday so we can confirm accommodation requirements with the hotel. In view of the short timespan please fax your registration form to me no later than Monday 3rd February 1997.

I look forward to hearing from you and to your participation in this meeting.

Yours sincerely



**Jilly Steward**  
*Meeting & Travel Manager*

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