

TAB U:  
 "ALL CORRESPONDENCE TO DATE (7/27/93) CONTAINED IN THE OFFICIAL GRANT FILE FOR 1R13HG00703-01"

Item	Date	FROM	TO	SUBJECT
	4/23/93			Notice of Grant Award
	8/05/92			Notice of Grant Award
	7/20/92			Notice of Grant Award
	4/30/92			Notice of Grant Award
Letter	4/22/93	Diggs	Medina	letter of termination
Memo	4/20/93	Healy	DHHS Secretary	"Termination of Conference Grant to the University of Maryland-INFORMATION"
Fax	4/20/93	Gottesman	Jordan	Draft of above memo "to assist you in the briefing of Dr. Collins"
		Diggs	Gottesman	
Memo	4/29/93	Collins	Healy	"Termination of Grant 1R13HG00703-01 on 'Genetic Factors in Crime: Findings, Uses and Implications'"
Memo	4/19/93	Healy	Diggs	" " " " " concurrence
Letter	3/23/93	Diggs	Goldhaber	that NIH take formal action prior to expiration of grant
Note	none	Cahill	FILE	"Request for Financial Status of R13HG00703, Wasserman"
Note	12/10/92	Jaeger	Diggs	"University of Maryland Genetics Conference" - information and options
Letter	11/24/92	Goldhaber	Diggs	Wasserman's working group not consulted on revised draft of brochure
Letter	10/6/92	Goldhaber	Diggs	encloses draft of revised brochure and memo from Wasserman with plans for outside consultants
				"Chronology of Major Events of the Proposed Conference" -- 6/91-9/11/92
Letter	9/4/92	Diggs	Goldhaber	responds to request to lift freeze and proposed alternative, and to Wasserman's comments in press

Letter	9/1/92	Goldhaber	Diggs	that NIH lift its freeze or fund alternative research agenda (as proposed in attached memo)
Letter	8/18/92	Diggs	Medina	
Memo	8/17/92	Gottesman	NIH Director	"Proposed University of Maryland ELSI Conference"
Letter	8/12/92	Jordan	Collins	
Memo	8/6/92	Juengst	Gottesman Jordan	"ELSI Update"
Memo	8/5/92	Juengst	Gottesman Jordan	"Possible ELSI discussions while I'm away"
Memo	8/5/92	Healy	Gottesman	"ELSI Program, NCHGR"
Memo	8/3/92	Exec. Sec.	ICD Directors	"ICD Directors' Meeting Highlights - July 22, 1992"
Memo	8/3/92	Jordan	Diggs	"Progress of University of Maryland Conference"
Memo	7/31/92	Jordan	Diggs	"ELSI Conference"
Memo	7/30/92	Jordan	Chamblee	"Review of Extramural ELSI Applications"
Letter	7/29/92	Jordan	Medina	
Letter	7/29/92	Medina	Jordan	
Memo	7/28/92	Juengst	Gottesman Jordan	"Advisory meeting for U. of Md. conference"
Memo	7/23/92	Gottesman	Healy	"ELSI Program of National Center for Human Genome Research"
Memo	7/22/92	Diggs	Gottesman	"Conference Grant 1R13HG00703-01"
Memo	7/21/92	Gottesman	Diggs	" " " "
	7/21/92			"Talking Points About R13 HG00703-01"
Letter	7/20/92	Thomas Jordan	Wasserman	placing a restriction on the award
Fax	7/17/92	Juengst	Beckwith	

Note	7/17/92	Diggs	Healy	attaches memo of 7/17/92 from Diggs to Gottesman that funds must be restricted
Letter (faxed and mailed)	7/17/92	Fisher	Healy	outside opinion; suggests revamping brochure
Memo	7/16/92			"FACT SHEET: ELSI Grant R13 HG 00703-01"
Letter	7/16/92	Langfelder	Ross	responds to info request with 6 items
Letter	6/29/92	Thomas	Wasserman	any material to be withheld from FOIA request?
Memo	6/24/92	Jordan	Thomas	"Conference on Genetic Factors in Crime"
Memo	6/24/92	Juengst	Jordan	"R13HG00703-01 'Genetic Factors in Crime: Findings, Uses, and Implications'"
Note (handwritten)	6/23/92	Erik (Juenst)	David (Wasserman)	"spread the word that your understated statement of the issues was not intended to reflect an endorsement of genetic solutions to social problems"
Memo	6/18/92	Fink	Ralbovsky	"Conference on Genetic Factors in Crime"
Letter	6/4/92	Lippman Wilker	Juengst	brochure and conference are "extremely troubling"
Letter	5/11/92	Hall Juengst	Wasserman	signatures needed for request for supplement
Letter	3/11/92	? Wasserman	Juengst	request for supplement
Letter	1/28/92	Juengst	Wasserman	Council letter
Letter		Juengst	Wasserman	transmittal of summary statement



National Institutes of Health  
National Center for Human  
Genome Research  
Bethesda, Maryland 20892

Ethical, Legal & Social Implications  
Building 38A, Room 617  
38 Library Drive MSC 6050  
(301) 402-4997  
(301) 402-1950 (Fax)

MEMO

DATE: August 4, 1995

TO: OD Staff (Francis, Elke, Kathy, Leslie, Anne, Jean) and Extramural Staff  
(Mark, Betty, Bob, Jane, Linda, Jean)

FROM: Elizabeth

RE: University of Maryland Conference

This is to inform you all that the University of Maryland's Conference, "Research on Genetics and Criminal Behavior" is scheduled to be held September 22-24, 1995. I have enclosed a copy of their letter of invitation and their conference brochure. Although I have not yet heard any rumblings about this conference, the PI and the University of Maryland are expecting some. As such, I think we here at the NIH ought to be prepared just in case a reaction occurs.

Francis, Elke, Mark-

As you will see I been invited to participate and would like to hear from you if you believe it would be wise for me to attend or not. Also, please let me know if I should let Building 1 know that this conference is scheduled. A couple of months ago I received a request for information about this conference from Wendy Baldwin, so I think she should be kept informed. If you want me to do this I will be happy to do so. Finally, if there is anyone else that you think I should keep informed about this conference other than the above identified people, I would be glad to hear from you.



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## UNIVERSITY OF MARYLAND AT COLLEGE PARK

INSTITUTE FOR PHILOSOPHY AND PUBLIC POLICY

July 26, 1995

Ms. Elizabeth J. Thomson  
National Center for Human Genome Research  
ELSI Branch  
Building 38A, Room 617  
38 Library Drive MSC 6050  
Bethesda, MD 20892

Dear Ms. Thomson:

I would like to invite you to attend a conference on "Research in Genetics and Criminal Behavior: Scientific Issues, Social and Political Implications." The conference will be held on September 22-24th at the Aspen Institute's Wye Center on Maryland's eastern shore. I enclose a brochure with information on the agenda and the participants. There is no registration fee for the conference, but you have the option of purchasing meals and snacks. You must arrange your own travel and accommodations, but we will be happy to assist you.

Enclosed is a copy of our Institute's Report, in which I discuss some of the issues the conference will address.

I would be grateful if you could let me know as soon as possible if you will be able to attend. Space at the Wye Center is very limited, and there is considerable interest in the conference. I will hold a space for you until August 15th.

Sincerely,

A handwritten signature in cursive script, appearing to read "David Wasserman".

David Wasserman  
Conference Director

DW/cl  
Encl.



National Institutes of Health  
National Center for Human  
Genome Research  
Bethesda, Maryland 20892

Building 38A, Room 605  
(301) 496-0844  
FAX 402-0837

CONFIDENTIAL

August 4, 1993

TO: Janet M. Cuca, Ph.D.  
NIH Appeals Officer, OD

FROM: Deputy Director, NCHGR

SUBJECT: Request for Information for Grant Appeal Board GA93-01

This information is provided in response to your memo of August 3. The answers are numbered according to your questions.

1 (a): The NCHGR received an information copy of Dr. Goldhaber's October 6 letter from the OD shortly after the letter was received in the OD. We have no record of the date.

1(b,c,d): The NCHGR staff discussed the draft revised brochure text extensively with Dr. Wasserman prior to its submission, but the NCHGR was not asked to review or make any recommendations regarding the material submitted with Dr. Goldhaber's October 7 letter.

2(a): The draft revised brochure provides an accurate introduction to the central subject of the conference: the social issues raised by the potential use of behavioral genetic claims within social institutions like the criminal justice system. It emphasizes the concerns of those skeptical of such uses, and thus better represents the views of the majority of speakers on the original roster.

2(b): As more links are made between human genes and human behavioral traits, the subject of this conference becomes even more timely. Several other meetings are now being planned by other institutions to pursue these discussions, on the assumption that it is feasible to do so. In part, this confidence draws from the success of a session on these issues at the 1993 national AAAS meetings. Given these developments, the U. of Maryland conference would require substantial revision if it were to take place now.

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Page 2 - Janet M. Cuca, Ph.D., NIH Appeals Officer, OD

3: Dr. Wasserman requested and received the NCHGR logo at the suggestion of NCHGR staff as a means of highlighting NCHGR funding for the conference. No review of the brochure was performed by NCHGR staff, however, prior to its publication.

*Elke Jordan*  
Elke Jordan, Ph.D.

- cc:
- Dr. Francis Collins
- Dr. Michael Gottesman
- Dr. Eric Juengst
- Ms. Jean Cahill

CONFIDENTIAL

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August 27, 1992

NOTE TO THE RECORD:

Subject: Notifying P.I. of Congressional Investigation

Chuck Sabatos called yesterday afternoon regarding the question of whether we can notify Dr. Wasserman about the Weiss inquiry. He suggested that we get guidance from Dr. Diggs on the correct procedure in these types of cases.



Cheryl McMillen



August 25, 1992

NOTE TO CHUCK SABATOS:

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Subject: Materials related to the conference, "Genetic Factors in Crime: Findings, Uses and Implications."

As you know, we have reviewed the packet of correspondence we sent to you on the above named conference in order to remedy cases where attachments or enclosures do not appear with cover notes, memos and letters. The information sent yesterday accompanying Dr. Gottesman's letter should help to clarify the matter.

However, there remains one note that refers to an unspecified attachment, and the purpose of my writing is to clarify that note. In the note of June 23 from Dr. Juengst to Dr. Wasserman, "the attached" refers to the article from The Rights Tenet, "The 'Violence Initiative'--A Racist Biomedical Program for Social Control." This article can be found in the packet we sent containing background and journal articles. I hope this information is useful and that the materials now can be more clearly understood.

Once again, please feel free to call me with any questions on 402-2205.



Cheryl McMillen

cc:  
Dr. Gottesman  
Dr. Jordan  
Dr. Guyer  
Mr. Vennetti  
Dr. Juengst  
Ms. Simon



National Institutes of Health  
National Center for Human  
Genome Research  
Bethesda, Maryland 20892

Building 38A, Room 605  
(301) 496-0844  
FAX 402-0837

August 24, 1992

TO: Chuck Sabatos  
Program Analyst, DLA

FROM: Acting Director, NCHGR

SUBJECT: Additional Material Related to the Conference on "Genetic  
Factors in Crime: Findings, Uses and Implications"

In response to the August 21 telephone request from your office, I am transmitting additional material related to the subject conference. The request was for attachments to the letter to Dr. Francis Collins, dated August 12, 1992 and to the FAX from Dr. Eric Juengst to Dr. Jon Beckwith, dated July 17, 1992. The documents in question were not included as attachments in the original package because they had already been included in other sections of the original package. However, we can understand the rationale for duplicating these documents as attachments as well as presenting them in other parts of the package.

Dr. Eric Juengst, who was on vacation when the original package was prepared, returned to the office today. In reviewing your recent request, he stated that the material sent by FAX to Dr. Jon Beckwith, was also sent to Drs. Robert Murray, Patricia King and Nancy Wexler. This information was not contained in our original submission, because there was no indication in Dr. Juengst's file that copies had been sent to these other individuals.

If you have further questions regarding this matter, please contact Cheryl McMillen on 402-2205.

Michael M. Gottesman, M.D.

cc: Dr. Elke Jordan  
Ms. Simon  
Ms. McMillen ✓

From the desk of the  
Associate Director for Extramural Affairs

AUG 18 1992



George J. Galasso, Ph.D.

Dr. Lotteman

Mike

I still have a little trouble with it and have suggested some changes in the title. "Predisposition" also gives us trouble and we made some suggestions there.

The other problem is can a conference grant be used to fund a book. Since the science is the same - since the outcome (collection and dissemination of information) is the same - we believe you can change the scope provided you get Council approval <sup>(mail?)</sup> and change the designation.

National Institutes of Health  
Building 1, Room 152

301-496-5356

301-496-0232 FAX

cc D. Jaeger

Diana Jaeger in our grants office can be of help

George

Series of Articles for Book

Working Draft  
From David Wasserman

~~Causation and Control~~; Political and Ethical Questions Raised by  
Research into Genetic, and Biological Factors in ~~Criminal~~ Behavior

Issues

~~Environmental,~~ contributing ~~to~~ ~~Illegal~~ ~~conduct~~  
to behavior which leads to illegal conduct

1) The Scientific Context

correlations sequential evidence a) <sup>IP and</sup> What is the evidence for genetic and biological ~~predispositions~~ related to criminal behavior? What kinds of ~~predispositions~~ do researchers claim to find or expect to find? What methodological and interpretive issues are raised by these claims and expectations?

2) The Philosophical Context

evidence a) What, if anything, does it mean to say that human behavior has a genetic or biological cause?  
b) How, if at all, should information about genetic ~~predispositions~~ affect the moral assessment of conduct?

3) The Juridical Context

a) How might evidence of genetic <sup>Factors</sup> ~~predisposition~~ be used or abused at criminal trials and sentencing?  
hard to address without including social factors

4) The Historical Context

a) What can we learn about the risks of present research from the history of abuses of genetic explanations of criminal and other behavior?

5) The Social and Political Context

a) Does the search for genetic and biological factors in <sup>illegal conduct</sup> ~~criminal~~ behavior risk creating tools or techniques that will be wrongly used against minorities?  
b) How does the search for genetic and biological factors affect public and professional perceptions of the locus of responsibility for the "crime problem" in the United States?  
c) How are those perceptions affected by the public discussion of research on genetic and biological factors?



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National Institutes of Health  
Bethesda, Maryland 20892  
Building : 38A  
Room : 605  
(301) 496-0844

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DATE: August 18, 1992

FROM: Acting Director, NCHGR

SUBJECT: Grant # 1R13 HG00703-01

TO: Chairman Ted Weiss, Subcommittee on Human Resources  
and Intergovernmental Relations,  
Committee on Government Operations

Given the sensitive nature of the records and the fact that we would not disclose them to other than Congress, we would greatly appreciate it if you would protect their confidentiality.

A handwritten signature in cursive script, reading "Michael M. Gottesman for".

Michael M. Gottesman, M.D.

Attachment

August 18, 1992

NOTE TO KRIS KISER:

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Subject: Notifying P.I. of Congressional Request

As per our phone conversation earlier today, we would like to determine the procedure for notifying Dr. Wasserman about the congressional request for materials related to his grant. So far, we understand that we are not required to inform the P.I. in this type of case, but that it would be a courtesy to Dr. Wasserman. From what I can determine, since the request came through the Office of Director, the notification to Dr. Wasserman should come from the Office of Director.

Can you please check on the correct procedure and let me know if/when Dr. Wasserman is informed of Chairman Weiss' request.

  
Cheryl McMillen

cc:  
Dr. Gottesman  
Dr. Jordan  
Dr. Guyer  
Mr. Vennetti  
Dr. Juengst  
Ms. Thomas  
Ms. Simon  
Ms. Fink



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

National Institutes of Health  
National Center for Human  
Genome Research  
Bethesda, Maryland 20892

Building 38A, Room B2N13  
(301) 402-2205  
(301) 402-2218

DATE: August 17, 1992

TO: Kris Kiser  
Program Analyst, DLA

FROM: Acting Director, NCHGR

SUBJECT: NCHGR Material Related to the Conference on "Genetics  
Factors in Crime: Findings, Uses and Implications"

In response to your request of August 14, 1992, I am transmitting all NCHGR material related to the conference, "Genetic Factors in Crime: Findings, Uses and Implications."

Please feel free to call Cheryl McMillen or Helen Simon at 402-2205 with any questions or for additional information.

  
Michael M. Gottesman, M.D.

cc:

Ms. Simon  
Ms. McMillen

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NATIONAL CENTER FOR HUMAN GENOME RESEARCH

*CORRESPONDENCE*

*RELATED TO THE CONFERENCE ON*

**GENETIC FACTORS IN CRIME:  
FINDINGS, USES AND IMPLICATIONS**



**INDEX OF NCHGR CORRESPONDENCE RELATED TO CONFERENCE "GENETIC  
FACTORS IN CRIME: FINDINGS, USES, AND IMPLICATIONS"**

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August 18, 1992 Letter

From Dr. Diggs

To Mr. Medina

Subject: Response to Medina letter

August 17, 1992 Memorandum

From Dr. Gottesman

To Dr. Healy

Subject: Proposed University of Maryland ELSI Conference

August 12, 1992 Letter

From Dr. Jordan

To Francis Collins (Identical letters were sent to all members  
of the National Advisory Council for Human Genome Research)

Subject: University of Maryland Conference

August 6, 1992 Note

From Dr. Juengst

To Drs. Gottesman and Jordan

Subject: ELSI Update

August 5, 1992 Note

From Dr. Juengst

To Drs. Gottesman and Jordan

Subject: Possible ELSI discussions while I'm away

August 5, 1992 Memorandum

From Dr. Healy

To Dr. Gottesman

Subject: ELSI Program, NCHGR

August 3, 1992 Memorandum

From Ms. O'Steen

To ICD Directors

Subject: ICD Directors' Meeting Highlights - July 22, 1992

August 3, 1992 Memorandum

From Dr. Jordan

To Dr. Diggs

Subject: Progress of University of Maryland Conference

July 31, 1992 Memorandum

From Dr. Jordan

To Dr. Diggs

Subject: ELSI Conference

July 30, 1992 Memorandum

From Dr. Jordan

To Ms. Chamblee

Subject: Review of Extramural ELSI Applications

July 29, 1992 Letter  
From Dr. Jordan  
To Mr. Medina  
Subject: University of Maryland Conference

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July 29, 1992 Letter  
From Mr. Medina  
To Dr. Jordan  
Subject: Conference Grant

July 28, 1992 Note  
From Dr. Juengst  
To Drs. Gottesman and Jordan  
Subject: Advisory Meeting for U. of Md. Conference

July 23, 1992 Memorandum  
From Dr. Gottesman  
To Dr. Healy  
Subject: ELSI Program of NCHGR

July 22, 1992 Memorandum  
From Dr. Diggs  
To Dr. Gottesman  
Subject: Conference Grant

July 21, 1992 Memorandum  
From Dr. Gottesman  
To Dr. Diggs  
Subject: Conference Grant

July 21, 1992 Talking Points  
From Dr. Juengst

July 20, 1992 Letter  
From Ms. Thomas and Dr. Jordan  
To Dr. Wasserman  
Subject: Restriction of Award

July 17, 1992 FAXED Note  
From Dr. Juengst  
To Dr. Beckwith  
Subject: University of Maryland Conference

July 17, 1992 Note  
From Dr. Diggs  
To Dr. Healy  
Subject: Restriction of Activity of Grant

July 17, 1992 Memorandum  
From Dr. Diggs  
To Dr. Gottesman  
Subject: Conference Grant

July 17, 1992

From Dr. Fisher  
To Dr. Healy  
Subject: Review of Conference

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July 16, 1992 Fact Sheet on ELSI Grant  
From NCHGR

July 16, 1992 Letter  
From Ms. Langfelder  
To Mr. Ross  
Subject: Information on the NCHGR ELSI Program

June 29, 1992 Letter  
From Ms. Thomas  
To Dr. Wasserman  
Subject: FOI Release of Grant Application

June 24, 1992 Memorandum  
From Dr. Jordan  
To Ms. Anne Thomas  
Subject: Conference on Genetic Factors in Crime

June 24, 1992 Memorandum  
From Dr. Juengst  
To Dr. Jordan  
Subject: Conference Grant

June 23, 1992 Note  
From Dr. Juengst  
To Dr. Wasserman  
Subject: Conference Grant

June 18, 1992 Memorandum  
From Ms. Fink  
To Mr. Ralbovsky  
Subject: Conference on Genetic Factors in Crime

June 4, 1992 Letter  
From Ms. Lippman and Ms. Wilker (McGill University)  
To Dr. Juengst  
Subject: Conference and Brochure

June 2, 1992 Congressional Record of Call  
From Ms. McMillen  
To Mr. Ismail  
Subject: Information on ELSI Program and Genetic Factors in  
Criminal Behavior (Brochure)

May 11, 1992 Letter  
From Ms. Hall and Dr. Juengst  
To Dr. Wasserman  
Subject: Grant Supplement

March 11, 1992

From Dr. Wasserman  
To Dr. Juengst  
Subject: Grant Supplement

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January 27, 1992 Council Letter

From Dr. Juengst  
To Dr. Wasserman  
Subject: PreCouncil Letter

January 27, 1992 Council Letter

From Dr. Juengst  
To Dr. Wasserman  
Subject: PostCouncil Letter



## DEPARTMENT OF HEALTH &amp; HUMAN SERVICES

Public Health Service

National Institutes of Health  
Bethesda, Maryland 20892

Post-it™ brand fax transmittal memo 7671 [redacted] 12

AUG 18 1992

Mr. Victor Medina  
Director  
Office of Research Administration and Advancement  
University of Maryland at College Park  
2100 Lee Building  
College Park, Maryland 20742-5141

Re: 1 R13 HG00703-01

Dear Mr. Medina:

Your letter of July 29 addressed to Dr. Elke Jordan regarding restrictions placed on the above referenced grant has been referred to me for response.

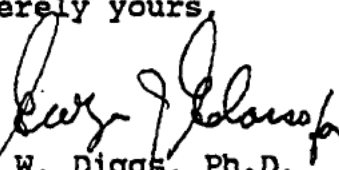
First, let me reiterate what was stated in the letter of July 20 from Dr. Elke Jordan and Ms. Alice H. Thomas. That is, the restriction imposed through the revised Notice of Grant Award is intended only as a temporary measure to allow for further discussions about the proposed conference. This action became necessary due to unanticipated sensitivity and validity issues raised following publicity about the conference. With regard to the authority to impose this restriction, Public Health Service (PHS) grants policy (PHS Grants Policy Statement page 5-3) permits modification of the terms of an award when consistent with applicable statutes and regulations and deemed to be in the best interest of the Government. The significance of the concerns, which have been discussed with Dr. Wasserman, necessitated the imposition of the restriction to assure and protect the interests of the public and the proper use of grant funds. NCHGR staff would be remiss in their responsibility if they did not seriously address these valid concerns.

Also of concern to staff is the statement in the brochure which indicates that the conference is "sponsored" by NIH. The Health and Human Services Appropriations Act requires that grantees acknowledge Federal support of projects or programs funded in whole or in part with Federal funds. However, the designation of NIH as a joint sponsor of this conference is inappropriate in that it implies our direct involvement in the planning and development of the program.

Page 2 - Dr. Victor Medina

In closing, let me assure you that staff of the NCHGR remain committed to working with Dr. Wasserman to alleviate all concerns in a satisfactory manner.

Sincerely yours,



John W. Diggs, Ph.D.  
Deputy Director for  
Extramural Research

cc:  
Dr. Wasserman  
Dr. Jordan  
Ms. Thomas



National Institutes of Health  
National Center for Human  
Genome Research  
Bethesda, Maryland 20892

Building 38A, Room 605  
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(301) 402-0837 (Fax)

August 17, 1992

**TO:** Bernadine Healy, M.D.  
Director, NIH

**FROM:** Acting Director, NCHGR

**SUBJECT:** Proposed University of Maryland ELSI Conference

Thank you for your detailed memorandum of August 5, 1992, clarifying your position on the proposed University of Maryland conference and on ideas to prevent a repetition of the problem we have encountered with this conference.

We have all learned to be sensitive to the complex issues which surround some (if not all) of our proposed ELSI grants. In the case of the University of Maryland conference on "Genetics and Crime" neither the initial peer review group nor the NCHGR Council, despite minority representation, anticipated the concern which has been raised by the African American community about the implications of NIH support for such a conference. In this case, as detailed in my memorandum of July 23, 1993, we have responded by asking the conference organizer, David Wasserman, to appoint an Advisory Group to help him reformat (and retitle) the conference to respond to concerns. He has met with the group and appears to be convinced that his conference is not likely to succeed in the present climate. We are working with him to find an alternative way to address the issues raised about studies on genetics and certain kinds of human behavior.

I would like to make it clear that we have been in complete agreement with you that the brochure describing the meeting and the issues this meeting planned to raise are areas of legitimate sensitivity to minority groups, and that it is entirely appropriate that these concerns be addressed promptly as you have advised. Dr. Wasserman's recent actions indicate that he, too, has become sensitized to this issue.

With respect to the prevention of future problems of this kind, we appreciate your openness to further briefing on the ELSI program and to discussion of ways to improve review of ELSI grants. As you know, we have invited Ms. Sandy Chamblee, Senior Policy Advisor and Counselor to the Director to attend meetings

Page 2 - Bernadine Healy, M.D.

of our ELSI Initial Review Group and our NCHGR Council meetings. In addition, Nancy Wexler, Chairman of our ELSI Working Group, has suggested that this group use the University of Maryland Conference as a case study to generate ideas for how problems of ~~this kind can be prevented in the future.~~ This group is meeting at the NIH on September 16, and would be pleased if you could speak to them about this issue.

*Michael M. Gottesman, M.D.*  
Michael M. Gottesman, M.D.

cc:

Dr. Elke Jordan  
Dr. Eric Juengst



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National Institutes of Health  
National Center for Human  
Genome Research  
Bethesda, Maryland 20892

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Building 38A, Room 605  
(301) 498-0844  
(301) 402-0837 (Fax)

August 12, 1992

Francis S. Collins, M.D., Ph.D.  
Department of Internal Medicine  
University of Michigan Medical Center  
3570 MSRB II  
Ann Arbor, Michigan 48109-0652

Dear Francis:

You may have noted the attached Nature magazine story about an ELSI project that you helped review at our January, 1992, National Advisory Council meeting.

I have attached the summary statement from the initial review of Dr. Wasserman's application, and (with her permission) a letter to Dr. Healy from Dr. Nancy Fisher, who was, as far as we can discern, the only reviewer actually contacted by NIH about this matter.

Clearly, we are going to have to be more alert to projects that might be construed to be offensive, and we hope you will help us with that task. Meanwhile, Dr. Wasserman is working hard with us to try to negotiate a resolution to this situation that will remove any offensive aspects from the conference.

I remind you that it is inappropriate for you to publicly discuss the Council's review of this project. However, we at NIH would welcome your thoughts about this unfolding situation. We will discuss this at the next Council meeting in September.

Sincerely,

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*Elke*

Elke Jordan, Ph.D.  
Deputy Director  
National Center for  
Human Genome Research

Enclosures

cc:

Dr. Michael Gottesman, NCHGR  
Dr. Eric Juengst, ELSI Branch



Aug.6, 5:15 pm

TO: Michael Gottesman  
Elke Jordan

FROM: Eric Juengst

RE: ELSI UPDATE

1) David Wasserman called to report that they have been dis-invited to the Ad Hoc Committee meeting on Monday.

Their contact, Dr. Tutman, was apologetic, but said he had overstepped his authority in inviting them before consulting the full group. Instead, the group will discuss on Monday whether they want to talk to Wasserman, and some members have already expressed opposition to the idea.

Wasserman is at a loss over what to do next, and is beginning to think about how best to explain things to his conferees, since they are soon going to start buying plane tickets, etc.

2) I talked at length with Nancy Wexler this p.m., and she would like to help reassure Bldg. 1 that this episode was one the program will learn from, by offering to have the Working Group take up the question of how best to avoid its repetition, and by helping with the Healy ELSI briefing. She wants to touch base with both of you on Monday when she is here for the search committee.

(She also pointed out that Kay Jamison's television special, "The Taint of Madness," recently resubmitted to us with Nancy as an advisor, could be misinterpreted just as badly.)

3) Mary Glynn tells me Francis Collins wanted to speak to me on Monday, while he is here. I wish I could do that, but it may be useful to fill him in anyway, as a council member, grantee and influential friend.

4) I have an appointment for an informal conversation with Sandy Chamblee at 11:30 Friday, arranged in the context of a very friendly phone call in which she commiserated over our treatment on Tuesday.

*Eric Juengst*



August 5, 1992

TO: Michael Gottesman  
Elke Jordan

FROM: Eric Juengst *EJ*

RE: Possible ELSI discussions while I'm away

Here are a few talking points in defense of the ELSI Program, if such should be needed while I'm away. These reflect the new critique offered by Dr. Diggs at the EPMC meeting this morning that we fully fund conferences (and, by implication, are profligate in other ways) just in order to meet our 5% goal.

1. This critique reflects a misapprehension about the program that is common in some segments of the scientific community: that NCHGR only does ELSI because Congress made us, and therefore we do it in an offhand way, creating in the process an federal entitlement program for ethicists and other biomedical hangers-on.
2. This misperception is dead wrong and flies in the face of the program's history and practice: We (or rather, Dr. Watson) initiated it, set the level of our commitment, and continue to be serious about doing it and doing it well.
3. The program (and DRG) have worked hard to establish an extraordinarily (for NIH) broad-based and expertly informed review process, which must have one of the highest "NR" rates at NIH. The range of voices involved means that ELSI money is not easy money, even for those few ELSI applicants who are skilled at NIH grantsmanship, as a visit to any study section meeting will demonstrate. Our funded portfolio is proof that the program has certainly not been "captured" by any particularly constituency, field, or perspective.
4. The bulk of the ELSI staff's work to date has gone towards bringing the attention of new (to NIH) communities to the Program's opportunities, convincing them that seeking support from NIH is worth their while, and helping them identify the ELSI questions their skills and experience can help address. Given the variety of communities necessary to our work (like genetic disease support groups, public educators, grass roots health policy organizations, and relevant disciplines from the social sciences, the law, and the humanities) it should not be surprising if our applications look

unusual by NIH standards, or that we seek out co-funding arrangements with other more experienced agencies (like NEH and NSF).

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5. Part of this program development effort has included a whole series of (fully funded) outreach conferences designed to open up new parts of the Program's agenda for research by relevant extramural communities --including the Maryland conference. These were not "scientific meetings" of NIH grantees in the usual NIH conference grant sense, but were designed to seed this new inquiry. The subsequent bulk of our ROI applications have come from participants in these ground-breaking meetings.

6. Our commitment to doing ELSI well will not prevent us from making management mistakes (like the U. of Md. conference brochure): the novelty and complexity of the program almost insures we won't do everything right the first time, despite our conscientious efforts to do so. Moreover, mistakes in programming ethical inquiries are likely to be offensive to some, almost by definition.

7. If possible (for a public program), these program management mistakes should be treated like mistakes in the inquiry itself: simply as events to from which to learn. Ethicists, like scientists, get used to making making mistakes in their work: they construct moral arguments towards some conclusion, which their colleagues criticize, pointing out the considerations that have been neglected, inconsistencies, etc., that make their conclusions ethically unacceptable (and possibly offensive). But being wrong, if intellectually embarrassing, is not considered to betray a character flaw. It is assumed that most ethical issues worth studying are complicated enough to confound our moral intuitions: they need to be thought about, which introduces the possibility of error. Similarly, it need not betray moral insensitivity for an ethics program to step in it offensively in trying to get off the ground: just inexperience.



AUG 05 1992

**TO: Michael Gottesman, M.D.  
Acting Director, NCHGR**

**FROM: Director, National Institutes of Health**

**SUBJECT: ELSI Program, NCHGR**

This is in response to your memorandum of July 23 regarding the Ethical, Legal and Social Implications (ELSI) Program of the National Center for Human Genome Research. Although I share your belief that the ELSI program is a bold and necessary departure from NIH tradition, which properly handled can be very positive, I strongly disagree with various aspects of your defense of that program.

First, I reject the notion that an internal committee or other mechanism to provide a special review of ELSI grants before funding would undermine the peer review process. That process assesses the fundamental scientific merit of the proposal in question and determines how the proposal fits into the program portfolio as a whole. When the NCHGR moves beyond science, as the ELSI program does, to fund grants addressing ethical, legal and social issues of critical importance to the community at large, particular sensitivity to the projects funded is warranted. In the case of ELSI grants, it may well be appropriate to augment the peer review process with another type of analysis of such grants. A specialized review, in addition to peer review, would reflect the NIH's heightened awareness of the uniqueness and societal importance of ELSI issues, rather than a lack of confidence in peer review.

Your July 1992 Grant-making Status Report of ELSI grants also suggests the need for a special tier of review for those grants. Not only would I challenge the propriety of funding the "Genetic Factors in Crime" conference as presently constituted, I would also question the ELSI program's support for the authorship of two chapters of a book on bioethics and feminist literature. Similarly, I would have questioned the prudence of funding the project, "The History of the Genetics of Blood Groups," whose methodology was "to compare the literature published during the period from 1919 to 1939 based on research done world-wide on blood group distribution as a definition of race and the links between blood type and criminality, insanity and disease." Particular caution in reviewing grants and approving funding for these types of topics is critical to the ELSI program's credibility and sustained support.

You are correct in your assertion that the ELSI program may be a "lightning rod" that will permit the airing of controversial issues in a controlled setting. However, we have to be very careful that the program itself does not become a lightning rod for justified criticism. Although the ELSI program should not shrink from treating the controversial issues of our time, I firmly believe that their treatment must be open minded and sensitive, especially to the concerns of the public we seek to serve through the program. Indeed, I believe it is simply responsible stewardship to insist that significant or sensitive issues affecting public policy be considered in a properly structured, balanced environment. Such consideration is the very hallmark of the NIH's traditions; not, as you suggest, a departure from those traditions.

With respect to the timing of any special review of ELSI grants, I understand the difficulty of interjecting another review between the study section and Council meetings. I am open to any mechanism that would serve the necessary purpose without undue disruption. However, I am sure that you would agree that having to restrict or withdraw a grant after it has been funded is even more disruptive than catching problems midway through the process. Consequently, I suggest that you consider this matter and work with Sandy Chamblee to come up with workable proposals for achieving the special level of review which I have recommended.

Second, I strongly disagree with your perception that any special review of ELSI grants would represent an effort "to impose political or other control above the quality of the scholarship." To label such a review "political" is specious and reflects a failure to appreciate fully the legitimate criticism leveled against the seminar on "Genetic Factors in Crime" by the African-American community. In checking on this conference with African-American members of various ELSI advisory groups, we found that a number of those members were unaware of the conference and were not willing to support it in its present form. As you know, the NIH has an obligation to earn and maintain the public trust in its biomedical and related sciences research and in the transfer of the fruits of that research to the public. When you attempt to dismiss the concerns raised by any of the NIH's constituents or the actions taken in response to those concerns by labeling them "political," you are saying that the NIH does its science in a vacuum and need not be responsive to the world around it. I would think that, of all the programs at the NIH, the ELSI program should appreciate and assiduously protect notions of public trust and responsibility.

The concerns raised by the proposed "Genetic Factors in Crime" conference relate directly to matters of public trust, despite

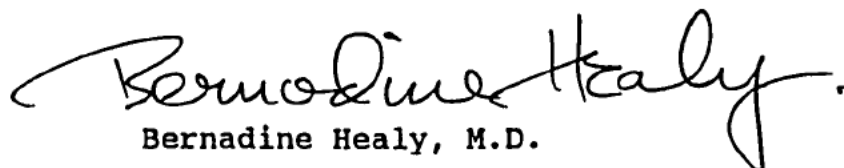
the fact that some individuals did not initially or even later appreciate the basis for or seriousness of those concerns.

Moreover, the fact that the concerns were raised by a particular segment of our society in no way undercuts their importance. Had we ignored those concerns and permitted the conference to go unchallenged, we might have done grave harm to the ELSI program and tarnished the NIH's reputation with the public. Because of the unique issues which fall within the ELSI program's purview, I believe that you should demonstrate a heightened sensitivity to these issues rather than labeling efforts to improve the process as "political." I truly believe that the ELSI program can foster full, frank, and open discussions of controversial topics with sensitivity and without ignoring the legitimate concerns of any segment of the population.

I offer the following responses to the particular proposals made in your July 23 memorandum:

1. I would welcome a briefing on the background, philosophy, activities and plans for the ELSI program. Perhaps such a briefing could include Eric Juengst and select members of your working group and Council.
2. To the extent possible, Sandy Chamblee will attend meetings of your study section and Council to obtain an understanding of their workings. Please give her as much advance notice as possible to avoid conflicts with other scheduled meetings.
3. With respect to my proposal for an intermediate grant review mechanism, as noted above I disagree that such a review is either unnecessary or problematic. However, I remain open to other suggestions to achieve the purpose of filtering inappropriate grants with the least disruption to your program while assuring public trust in the NIH's commitment to deal with issues of societal concern.

The ELSI Program represents a vital innovation for the NIH to respond to genuine public concerns about our scientific research. We must assure that it strongly fosters rather than undermines the public trust in this institution. I remain resolute in that position, but am committed to work with the NCHGR to attain our mutual goals.

  
Bernadine Healy, M.D.





AUG 6 1992

National Institutes of Health  
Bethesda, Maryland 20892NCHGR.  
Watson  
38A/605  
S.

August 3, 1992

TO: ICD Directors

FROM: Director, Executive Secretariat

SUBJECT: ICD Directors' Meeting Highlights - July 22, 1992

1. Sexual Harassment Allegations

Dr. Healy discussed a very serious case of alleged sexual harassment that was brought to her attention within the last few days. Several women and men have written her about the same case, in which the harassment appears to have taken place over a period of years; Dr. Healy termed their allegations shocking and said sexual harassment is unacceptable and intolerable and cannot continue at NIH. Every NIH manager will be held accountable for helping to solve sexual harassment allegations. These efforts will be examined during the performance appraisal process.

Ms. Armstrong reminded the group that unlike other EEO complaints, once a manager becomes aware of allegations of sexual harassment, he or she must conduct an inquiry, even if the manager must do so without the permission of the person being harassed. She promised to provide information to all ICD Directors on what constitutes sexual harassment and the responsibilities of managers in dealing with it. Dr. Healy asked Ms. Armstrong to help each ICD Director determine whether they have done an adequate job of informing their employees about what constitutes sexual harassment and creating a climate within which sexual harassment will not be tolerated.

Dr. Diggs added that this case has even broader implications, since it may involve grantees. This is of particular importance to him since it could call into question the integrity of the entire peer review process and how the outside world perceives NIH.

Dr. Healy reiterated her belief that while such harassing behavior may be an illness and should be dealt with sensitively, such behavior will not be tolerated at NIH.

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2. Intramural Trials

Dr. Alexander provided an update on an NICHD intramural trial involving human growth hormone. Mr. Jeremy Rifkin and his Foundation for Economic Trends petitioned to halt the trial. Dr. Healy is concerned that this trial had no independent data safety and monitoring board. She said that having a drug company control the data exposes NIH to charges of poor data management. Therefore, an external data safety and monitoring committee has been established to review the study, and no additional patients will be accrued until this review has been completed. In addition, data collection is being transferred from Eli Lilly to a data center supported by NICHD. Mr. Rifkin is being informed of these steps and his petition will be answered after a decision has been made about whether to continue the trial.

ACTION: Dr. Healy asked ICD Directors to carefully review all their intramural clinical trials and CRADAs for similar situations or other potential conflicts of interest.

3. ELSI Issues and Policies

Dr. Gottesman discussed the status of NIH-supported ethical, legal, and social issues (ELSI) research. NCHGR's program consists primarily of investigator-initiated research grants and conferences. Some of the topics being looked at, such as the University of Maryland's Genetic Factors and Crime Conference, are controversial; the principal investigator in this case wanted to examine the implications of the notion that genetics play a role in crime. Unfortunately, the fliers he sent to announce the conference raised a number of concerns. The grant was approved and funded as of July 1, but NCHGR funds have been frozen while an advisory committee is formed to decide how to reformat the conference. NCHGR will ensure that minorities are represented on the committee and that the entire committee understands the full implications and sensitivities surrounding the issues.

Dr. Healy suggested the possibility of having a second group review ELSI grants after peer-review but before discussion by a national advisory council to help ensure that sensitive topics are carefully considered from all points of view. She also suggested that each ICD review its portfolio and make sure every grant is relevant and appropriate.

Dr. Healy stressed that while it is important to study ELSI issues, there is no reason they can't be studied intramurally as well as extramurally. She suggested that these issues might be appropriately taken up within the policy center that Ms. Chamblee is working to establish within OSPL.

4. Information Items

While there is no further news on the FY 1993 budget, Dr. Healy gave a presentation on NIH's FY 1994 budget to Mr. Tom Scully, an OMB Program Associate Director. The meeting went well, and (with the approval of both PHS and the Department) we are actively seeking to make NIH a Presidential initiative. In the past NIH has dealt with OMB at a much lower level, and Mr. Mahoney termed this meeting a breakthrough.

Dr. Moskowitz emphasized the importance of completing the strategic plan and distributed a schedule for doing so (attached). He also distributed a follow-up document July 21, which includes the complete draft plan. The goal is to have a document to Dr. Healy by the third week of August and a product to the Department soon after that. Dr. Healy stressed the importance of producing a good, crisp document without redundancies or superfluous information.



Karen Pelham O'Steen

cc: OD Staff

Attachment

**DIRECTOR'S RETREAT--Follow-up**

(Tab A)

(Tab C)

(Tab A)

Activity	NIH "Objective" Chairs e.g. Critical Science & Technology	Extramural Chairs	Intramural Panel Members	Area of Emphasis Report Framers/Editors e.g. Molecular Medicine	NIH ICDS NIMH, NIDA NIAAA, OD Staff	Due Dates	
Provide rapporteurs notes to report editors.	X					July	23
Revise reports based on input from Director's Retreat, National Task Force meeting, other discussions.				X		July	29
Forward revised reports to <u>extramural</u> trans-NIH objective chairpersons.	X	(e.g. Dr. Sharp MIT)				Aug.	3
Extr. comments due to NIH "Objective" chair offices.		X				Aug.	7
Convene trans-NIH objective panels (intramural members) to review proposed report revisions.	X		X	X	as appropriate	Week of Aug.	10
Revised reports due to OSPL.	X					Aug.	14
Final review of reports.					X	Aug.	21



National Institutes of Health  
National Center for Human  
Genome Research  
Bethesda, Maryland 20892

Building 38A, Room 605  
(301) 496-0844  
(301) 402-0837 (Fax)

August 3, 1992

**TO:** John W. Diggs, Ph.D.  
Deputy Director for Extramural Research

**FROM:** Deputy Director, NCHGR

**SUBJECT:** Progress of University of Maryland Conference

Dr. Wasserman has spoken to two prominent members of the Ad Hoc Committee against the Federal Violence Initiative, Dr. Ronald Walters, Professor of Political Sciences, Howard University and Dr. William Tutman, Director of the Center for Combatting Violence, Temple Hills, Maryland, requesting their aid in formulating a viable vehicle for discussing social issues in behavioral genetics research.

They were receptive to Wasserman's overture and have invited him and his colleague, Alan Strudler, to attend the Committee's regular meeting on Monday, August 10, to discuss his conference plans. They anticipate a group of 10 to 15 and Wasserman will report back to us and his Advisory Committee with the results and implications for his plans.

  
Elke Jordan, Ph.D.

cc:  
Dr. Bernadine Healy  
Dr. Michael Gottesman

bcc:  
Dr. Eric Juengst

NIH:NCHGR:EJuengst:cem:402-0911



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July 31, 1992

TO: John Diggs, Ph.D.  
Deputy Director for Extramural Research, OD

FROM: Deputy Director, NCHGR

SUBJECT: ELSI Conference

We had the first meeting of the advisors concerning the University of Maryland conference yesterday. Dr. Wasserman, Dr. Robert Murray, Dr. Getshon and Dr. Duster (by phone) were present, as well as Dr. Juengst and myself. We met for about two hours and discussed the issues from all perspectives. Dr. Murray informed us about a group called The Committee Against the Federal "Violence Initiative" that has made it their objective to stop the conference. It was decided that a first step should be for Dr. Wasserman to meet with Dr. Ronald Walters, a member of the committee, to discuss their concerns. Once that is done, he will report back and we will continue the discussion of how to proceed. I will keep you posted.

Both Science and Nature have now called about the conference.

  
Elke Jordan, Ph.D.

cc:  
Dr. Michael Gottesman  
Dr. Eric Juengst  
Ms. Alice Thomas

NCHGR:OD:EJORDAN:cem



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July 30, 1992

**TO:** Ms. Sandy Chamblee  
Senior Policy Advisor, OD

**FROM:** Deputy Director, NCHGR

**SUBJECT:** Review of Extramural ELSI Applications

I am sorry that you were unable to attend the recent DRG review group meeting evaluating grant applications submitted to the ELSI program. I realize that our invitation was offered on short notice, and that you already had meetings of your own scheduled on that day.

The applications reviewed on July 24 will also be discussed by the National Advisory Council for Human Genome Research on Monday, September 21. At that point, the written reports from the initial review group will be available, and the Council will be discussing the policy and programmatic dimensions of the recommended projects. I would like to invite you to attend that meeting as well. As the agenda for the Council meeting is developed, we should be able to give you the approximate times on September 21 when the ELSI applications will be discussed. I would also be pleased to schedule the ELSI review to accommodate your schedule to the extent possible.

Please let me know if you would like to attend the Council meeting. I believe you would find it interesting and informative.

Elke Jordan, Ph.D.

cc:  
Dr. Michael Gottesman  
Dr. Eric Juengst



July 29, 1992

Mr. Victor Medina  
Director  
University of Maryland at College Park  
Office of Research Administration  
and Advancement  
2100 Lee Building  
College Park, Maryland 20742-5141

Re: 1R13 HG00703-01

Dear Mr. Medina:

This is to acknowledge receipt of your letter of July 29, 1992, and to inform you that it has been forwarded to the Deputy Director for Extramural Research, NIH and his staff for response. As was stated in NCHGR's July 20, 1992 letter, the Director and the Deputy Director for Extramural Research, NIH requested that the restrictions be placed on the above referenced grant. Therefore, Mr. Geoffrey Grant, the NIH Grants Policy Officer, and Dr. John Diggs, will prepare a response. Please understand that I have no authority to lift the restriction on the grant under the circumstances. I am pleased, however, that Dr. Wasserman is meeting with an advisory committee to discuss any modifications that may be needed in the conference materials and I trust that we will soon reach a satisfactory resolution of the issues raised.

Sincerely,

/s/

Elke Jordan, Ph.D.  
Deputy Director  
National Center for Human Genome  
Research

cc: Dr. Wasserman  
Dr. Diggs  
Mr. Grant

Prepared by: A. Thomas, 7/29/92  
bcc: Dr. Gottesman, Eric Juengst, Official File, Board File, GMS



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AUG - 4 1992



## UNIVERSITY OF MARYLAND AT COLLEGE PARK

OFFICE OF RESEARCH ADMINISTRATION AND ADVANCEMENT

July 29, 1992

Dr. Elke Jordan  
Deputy Director  
National Center for Human  
Genome Research  
National Institutes of Health  
Bethesda, MD 20892

RE: Conference Grant GNM (AHR-S1) 1-R13 HG00703-01 "Genetic  
Factors in Crime: Findings, Uses, and Implications"

Dear Dr. Jordan:

This is in response to your letter of July 20, 1992, to Dr. David Wasserman notifying the University that NIH has placed restrictions on the above conference grant, and that no further expenditures may take place from these previously awarded funds. You state that "issues associated with the sensitivity and validity of the proposed conference" must now first be resolved before the award may proceed. We are informed that NIH has taken this action in consequence of criticism of the subject matter to be debated at the conference. We must formally object.

As you are aware, this was a refereed award. It was granted following a full exposition and review of the project. The terms and conditions were set forth and referenced in the Notice of Grant Award dated April 30, 1992. We are aware of no rule, law or regulation which would authorize the interruption of this award, or permit its unilateral modification at this time under these conditions. Accordingly, because the conference has been publicly announced and scheduled for October, 1992, and time is of essence, we ask that NIH immediately either:

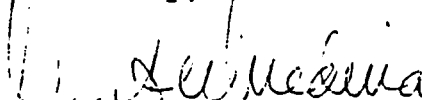
1. Completely lift its restriction on these grant funds and make them available in accordance with the Notice of Grant Award; or,
2. State explicitly and in writing the complete reasons, background, and authority for the restrictions you have imposed. In particular, provide the University with:

- (a) a statement of the complaint and the source of the complaint precipitating your action; and,
- (b) a complete statement of the "issues of sensitivity and validity" which serve as the basis for your action; and,
- (c) the operative definition and standard of "sensitivity" and "validity" used by you in restricting this award, together with a reference to the source thereof; and,
- (d) a reference to the rule, law, regulation, term or condition upon which you rely in restricting this award on account of "issues associated with sensitivity and validity".

In your letter you note a proposed "Advisory Committee" to assist Dr. Wasserman in modifying conference materials "to alleviate the concerns or clarify the issues that have been raised". We read this to be a condition necessary to a possible future release of the awarded funds. This constitutes the imposition of a unilateral change and post-award condition which the University believes is unauthorized. It is one to which we cannot agree, and must reject. Dr. Wassermann, of course, is certainly agreeable and will, in fact, meet with individuals recommended by NIH to discuss the administration of this grant. But he does so informally and as a colleague seeking advice and perspective. He would do this in any case and in the normal course of events. Please understand, therefore, that in meeting with them neither the University, nor Dr. Wasserman acquiesces in or ratifies this new condition or the restrictions now placed on this grant.

We would appreciate you giving this matter your earliest possible attention and we await your reversal of these restrictions no later than July 31, 1992.

Sincerely,

  
Victor Medina  
Director

VM/tsm

cc: Alice H. Thomas, Grants Management Officer  
Dr. David Wasserman, Principal Investigator  
Dr. Tim Ng, Dean - Graduate School  
Dr. Bruce Fretz, Acting Associate Provost

July 28, 1992

TO: Acting Director, NCHGR  
Deputy Director, NCHGR

FROM: Acting Chief, ELSI Branch

RE: Advisory meeting for U. of Md. conference

A meeting of advisors to the U. of Md. conference on social issues in behavioral genetics research has been scheduled for Thursday, July 30, in Conference Room 10 of Building 31.

The attendees will include the conference co-directors from the U.Md. Institute for Philosophy and Public Policy, David Wasserman JD, and Alan Strudler, JD, and the following advisors:

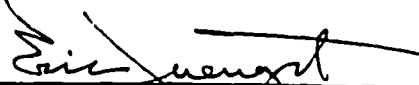
Troy Duster, Ph.D.  
Center for Social Change  
Department of Sociology  
University of California, Berkeley

Eliot Gershon, Ph.D.  
Clinical Neurogenetics Branch  
National Institute of Mental Health

Robert Murray, M.D.  
Department of Medical Genetics  
Howard University

David Wilkins, JD  
Program on Ethics and the Professions  
Harvard University

This group will be meeting to discuss changes in the conference publicity and program that may be necessary to address the concerns raised in response to the meeting's initial brochure.

  
Eric T. Juengst, Ph.D.



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July 23, 1992

**TO:** Bernadine Healy, M.D.  
Director, National Institutes of Health

**FROM:** Acting Director, NCHGR

**SUBJECT:** ELSI Program of National Center for Human Genome Research

As I indicated at the last Executive Committee meeting of July 22, 1992, when the Ethical, Legal and Social Implications (ELSI) program was started, it was clear to all involved that it was a bold departure from NIH traditions and that there would be controversy associated with some of its activities. If there were not, the ELSI program would not be doing its job. It was designed as the lightning rod that would allow controversial issues to be aired in a relatively controlled setting, while trying to resolve them through open discussion and education.

Of course, we want to avoid having our efforts misinterpreted, as they have recently been, in ways that offend people. However, I fully expect the program to arouse debate from time to time. In fact it must, if it is to succeed in its mission. I know you understand the need to stir the pot occasionally to generate ideas. On the other hand, we are as interested as you are in minimizing the negative impact on NIH. Properly handled, I believe, as I think you do, that the ELSI activities will be a very positive note for NIH. They certainly have already brought much credit to NIH for its willingness to entertain such an experiment.

In this regard, I would like to make a couple of proposals aimed at ensuring that ELSI lives up to its promise:

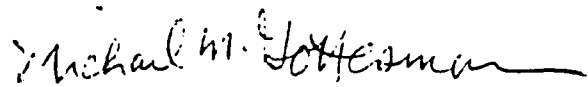
1. I request an opportunity for us to brief you on the background, philosophy, activities, and plans of the ELSI program. This would be complementary to the briefing on genome science we gave you a few weeks back, which was definitely useful for us and I hope for you. We would look forward to discussing the nature of the program and hearing your thoughts about it. I will call Vida Beaven to see if a place on your calendar can be found.

2. I believe it would be beneficial if Sandy Chamblee could attend the reviews of ELSI grants as well as ELSI working group meetings, so that she can get an appreciation of the extent of activities that the ELSI program is engaged in as well as the nature of the communities that we deal with. We have already invited her to the upcoming study section meeting on July 24. In the past Charles McKay has also attended on several occasions. In this way, Sandy could help us to identify policy implications or other sensitivities, which could then be discussed among staff to resolve any problems.

You probably realize that I am concerned that your proposal to set up an internal committee to provide an additional review of ELSI grants would pose a number of problems. Scheduling a meeting between study section and Council is difficult because Summary Statements generally are available only at the last minute. The timing of different ICD's Councils would be an added complexity. More importantly, such a review might be interpreted by the outside community as indicative of a lack of confidence in peer review or even as an attempt to impose political or other control above the quality of the scholarship as the determinant of funding. This could seriously undermine confidence in the program and might lead to agitation for moving it outside NIH.

The NIH is in the midst of learning how to foster frank and open discussions of the social implications of the research we support, and a crucial feature of the NCHGR's efforts has been to try to create a review environment which is hospitable to a diversity of extramural voices. The concern you raised about NIH not having the expertise to analyze ELSI issues has been dealt with by careful choice of peer reviewers with a range of talents and interests in ethical, legal and social matters. We must continue to trust their advice yet encourage their increased sensitivity to minority concerns.

One of our challenges in launching the program has been to convince constituencies who have concerns about advances in science that they can really expect to win support through the NIH peer review system. Any policy decisions on the part of NIH that suggest that ELSI applicants will face unique hurdles in gaining NIH support will immediately undercut these outreach efforts.

  
Michael M. Gottesman, M.D.  
Acting Director

cc:  
Dr. John Diggs  
Ms. Sandy Chamblee

## DEPARTMENT OF HEALTH &amp; HUMAN SERVICES

Public Health Service

National Institutes of Health  
Bethesda, Maryland 20892

July 22, 1992

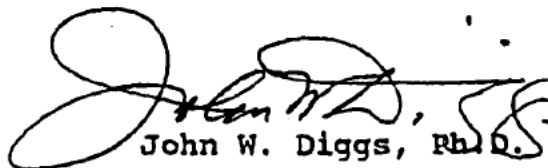
TO: Michael Gottesman, M.D.  
Acting Director, NCHGR

FROM: Deputy Director for Extramural Research, NIH

SUBJECT: Conference Grant 1 R13 HG00703-01

This is in response to your memorandum of July 21 concerning the conference grant, "Genetic Factors in Crime: Findings, Uses, and Implications". I appreciate the prompt action that you have taken to restrict the funds until the outstanding issues can be resolved.

I also appreciate the fact that Dr. Wasserman, the principal investigator, is enthusiastic about working with an advisory committee to address the issues of sensitivity and validity of the conference. Therefore, I approve your request to modify the restriction and permit the grantee to charge the costs of Dr. Wasserman's salary corresponding to the effort involved in working with the advisory committee. If these matters are resolved satisfactorily, we will jointly consider removing the balance of the restriction.



John W. Diggs, Ph.D.

National Institutes of Health  
National Center for Human  
Genome Research  
Bethesda, Maryland 20892

Building 38A, Room 605  
(301) 496-0844  
FAX 402-0837

July 21, 1992

TO: John W. Diggs, Ph.D.  
Deputy Director for Extramural Research, NIH

FROM: Michael Gottesman, M.D.  
Acting Director, NCHGR

SUBJECT: Conference Grant 1 R13 HG00703-01

We have received your memorandum of July 17, 1992, and have restricted the funds for 1 R13 HG00703-01 as you requested. There are several considerations I wish to bring to your attention regarding the broader implications of this action.

1. This action risks being misinterpreted as a lack of confidence by the NIH in the extramural peer review process. Following my discussions with you and other concerned NIH officials, as well as two members of our ELSI working group (Patricia King and Robert Murray), we conceived the idea of asking Dr. Wasserman to convene a new Advisory Group to reformat his conference to address their concerns. He was enthusiastic about the idea and is willing to reframe the conference to avoid offending concerned communities. Given our active steps in this direction, the official, public freezing of funds may be unnecessary. Several members of the advisory group have already been identified and agreed to serve (including Dr. Robert Murray, Howard University and Dr. Troy Duster, UC-Berkeley), and a meeting is being arranged next week on the NIH campus.
2. This action may be viewed as a retreat by the NIH from our commitment to anticipate and address the potential uses and abuses of ongoing (i.e. "unproven") scientific research. The ELSI Branch at NCHGR and the Center for Science Policy Studies within the NIH Director's Office were created explicitly to anticipate the social consequences of new biomedical research initiatives and their applications. These consequences often turn on the misuse of unproven scientific claims.

Page 2 - John W. Diggs, Ph.D.

3. Public concern about the legitimizing influence of federal funding is ~~directed primarily towards the actual research projects in behavioral genetics~~ under scrutiny at this conference. Restricting this conference's funding in response to this concern may raise questions about our willingness to directly scrutinize publicly supported research programs like those proposed under the "violent and self-destructive behavior" initiative of the NIH strategic plan.

In light of these considerations, we suggest that, at the least, the restriction on funding for this project be modified to allow for support of Dr. Wasserman's efforts to reframe the conference with his Advisory Group. It seems appropriate that he should be able to draw salary for his time. We plan to support the advisors through professional service contracts.

*Michael Gottesman, M.D.*  
Michael Gottesman M.D.



July 21, 1992

Talking Points About R13 HG00703-01

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1. The Ethical, Legal, and Social Implications (ELSI) Branch of the NCHGR was established explicitly to anticipate the ethical and social consequences of the application of new research initiatives in human genetics, specifically those originating from the Human Genome Project. The HGP is developing technologies that promise to make the search for genes in human DNA easier and cheaper. The ELSI Branch has issued a Program Announcement to solicit scholarly research in this area. Proposals submitted to the ELSI Branch are peer reviewed in the usual NIH manner and receive final approval by the National Advisory Council on Human Genome Research.
2. Research to determine a genetic contribution to violent and criminal behavior has always been emotionally charged. On that background, such studies are nevertheless currently underway in both public and private research institutions. It is consistent with the mission of the ELSI program to support discussions of the potential social risks of such studies *before* scientific conclusions are drawn, so policy makers can prepare socially and ethically responsible options to deal with the outcomes of these studies. To examine the scientific soundness of such studies, the assumptions on which they are based, and the social and judicial implications of the findings, NCHGR is funding a grant (R13-HG00703-01) to support a conference at the University of Maryland's Institute for Philosophy and Public Policy, October 9-11, 1992, on the College Park campus. The proposal to fund this conference came to the ELSI program through the usual research grants channels.
3. R13 HG00703-01 was reviewed and highly rated by a racially and ethnically diverse peer review committee on November 17-19, 1991. Reviewers felt the grant addressed concerns appropriate to the ELSI program and the field of human genetics research. The grant was approved by the National Advisory Council on Human Genome Research January Council in January 1992, and awarded April 30, 1992. NCHGR believes the grant application was appropriately reviewed.
4. Activities of the NCHGR, ELSI Branch, and the IPPP are in no way related to any biomedical research initiatives to study the biological or genetic contributions to violent behavior.
5. ELSI research is by its nature often controversial, and the ELSI program makes every effort to be sensitive to cultural concerns. Historically, genetic explanations of violent behavior have been used to bolster discrimination against population subgroups, particularly based on race. Conference organizers and NCHGR staff have recently become aware of the concerns of some individuals that materials to publicize the conference may not accurately reflect the tone or goals of the conference. Concerns have been raised that focussing on the genetic contributions in such a conference would not give appropriate balance to other factors that contribute to violent behavior, such as

social and economic conditions.

6. Until these concerns are resolved, the NIH has exercised its prerogative to halt temporarily further payment of funds on R13-HG00703-01. NCHGR, the grantee, and a group of advisors are currently working to ensure that the publicity materials and conference agenda are broadened to address the concerns raised, so the important work of the conference can proceed in an atmosphere that is culturally sensitive.

Other Contacts:

- 1. Robert F. Murray, M.D.,  
Department of Pediatrics  
Howard University  
[Redacted]
- 2. Patricia King, J.D.  
Georgetown University Law Center  
[Redacted]
- 3. Geoff Grant  
NIH Grants Management Policy

Other contacts:

- 1. Nancy Fisher
- 2. Bob Murray
- 3. Patricia King



July 20, 1992

Dr. David T. Wasserman  
Research Scholar  
Institute for Philosophy & Public Policy  
Room 0123 Woods Hall  
University of Maryland  
College Park, Maryland 20742

Dear Doctor Wasserman:

In response to a request from the Director and the Deputy Director for Extramural Research, National Institutes of Health (NIH), we are placing a restriction on the award of the conference grant entitled "Genetic Factors in Crime: Findings, Uses, and Implications".

As Dr. Gottesman discussed with you on Friday, July 17, issues associated with the sensitivity and validity of the proposed conference must be resolved. Until this is accomplished, all funds awarded under 1R13 HG00703-01 are restricted and no further expenditures may take place. This is a temporary measure to allow discussions to proceed concerning the implications of the conference that is planned.

You have indicated in discussions with Dr. Gottesman that you will engage an advisory committee to help you review all conference materials and plans with the goal of identifying modifications that may be needed to alleviate the concerns or clarify the issues that have been raised. We look forward to working with you on this and trust that a resolution agreeable to both you and the NIH can be found. Dr. Eric Juengst will be in touch with you to discuss details later.

Sincerely yours,

Alice H. Thomas  
Grants Management Officer  
National Center for Human  
Genome Research

Elke Jordan, Ph.D.  
Deputy Director  
National Center for Human  
Genome Research

cc: Dr. Mark Sagoff  
Mr. Victor Medina  
Dr. Bernadine Healy  
Dr. John Diggs

NIH:NCHGR:C. TIPPERY:402-0733

bcc: Dr. Gottesman, Dr. Jordan, Geoff Grant, Official File, Board File  
Dr. Juengst

NATIONAL CENTER FOR  
HUMAN GENOME RESEARCH, NIH

FAX TRANSMITTAL SHEET

TO: Jon Beckwith 617-738-7664

FAX NUMBER:

FROM: Eric T. Juengst, Ph.D.  
Director, ELSI Program

DATE: July 17, 1992

# of pages including cover sheet: 21

Return FAX number: [REDACTED]

If there are problems, call [REDACTED]

Comments: Help!

I have attached some information in anticipation of calling you to ask your advice on an unfolding problem here. As you'll see, we are funding a conference Oct. 9-11 at the Univ. of Maryland looking at the assumptions, methods and social consequences of ongoing behavioral genetics research on violence, with a focus on criminal justice implications. This meeting has been misinterpreted by the critics of such research as promotional, since its title starts with "Genetic Factors in Crime." I've attached a transcript from a TV talk show in which the conference is cited as evidence of a racist conspiracy by NIH to blame urban violence on inner city youth. In response to pressure, Dr. Healy has frozen the funds for this conference, which did very well in a well balanced peer review (roster attached). The conference organizers are willing to reframe the conference, but not under the threat of a funding freeze, to which they will eventually react legally and loudly.

Would you be willing to review the attached information and advise Michael Gottesman (Acting NCHGR Director), Elke Jordan and I as we strategize about how to pursue this issue to the hierarchy?

I will call after 2:00 today, and even some phone advice would be helpful.

Deputy Director  
for Extramural  
Research

Building 1, Room 144  
National Institutes of Health  
Bethesda, Maryland 20892  
(301) 496-1096  
(301) 496-0232 FAX



Dr. Healy

7-17-92

Everybody is now in agreement with the approach to restrict any further activity under Grant R13-HG00703 - Genetic Factors in Crime until the issues are resolved. The P.I. after looking at the Printed Flier advertising the conference also agrees that a problem does exist. I advised Audrey Manley of the steps we have taken.

U.S. DEPARTMENT OF HEALTH  
AND HUMAN SERVICES  
Public Health Service  
National Institutes of Health

Thanks for your support  
*John*  
108643



DEPARTMENT OF HEALTH & HUMAN SERVICES

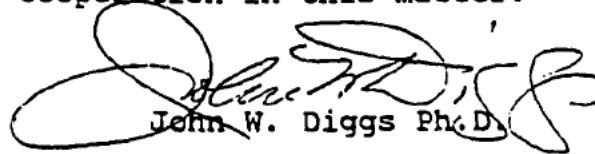
Public Health Service

National Institutes of Health  
Bethesda, Maryland 20892

DATE: July 17, 1992  
TO: Director, National Center for the Human Genome  
FROM: Deputy Director for Extramural Research, NIH  
SUBJECT: Conference Grant 1 R13 HG00703-01

This memorandum is to inform you the Director, National Institutes of Health (NIH) and I, in consultation with other senior staff, have determined that before any further activity can take place under grant 1 R13 HG00703-01 that issues associated with the sensitivity and validity of the proposed conference must be resolved. It must be determined if it is appropriate to use NIH funds to address the uses and implications of research data that have not been proven to be scientifically valid. Additionally, there are concerns that the presence of NIH funds would serve to legitimize the use of biological determinants to predict the likelihood of criminal behavior. Until these issues are resolved, all funds awarded under Notice of Grant Award 1 R13 HG00703-01 are restricted and no further expenditures may take place.

We are interested in resolving these issues with you and the grantee in the very near future. In the meantime, you should proceed to restrict the funds under the grant immediately. I appreciate your cooperation in this matter.



John W. Diggs Ph.D.

# DRAFT

Dear (Principal Investigator)

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(Business Official)

This memorandum is to inform you that staff of the National Institutes of Health (NIH) have determined that before any further activity can take place under grant 1 R13 HG00703-01, that issues associated with the sensitivity and validity of the proposed conference must be resolved. We must determine if it is appropriate to use NIH funds to address the uses and implications of research data that have not been proven to be scientifically valid. Additionally, there are concerns that the presence of NIH funds would serve to legitimize the use of biological determinants to predict the likelihood of criminal behavior. Until these issues are resolved, all funds awarded under Notice of Grant Award 1 R13 HG00703-01 are restricted and no further expenditures may take place.

We are interested in resolving these issues with you in the very near future. You may expect to hear from us by Wednesday July 22. We appreciate your cooperation with this matter.

Sincerely,

(Director HG)

NANCY L. FISHER

M.D., M.P.H.

MEDICAL GENETICS

FAXED AND MAILED

July 17, 1992

Bernadine Healy, M.D.  
Director, NATIONAL INSTITUTES OF HEALTH  
Building 1, Room 126  
Bethesda, Maryland 20892

Dear Dr. Healy:

I have re-read the proposal in question. This is not a study to use DNA markers for the study of criminality. Nor does it advocate such research. Nonetheless, the grantees point out that such research has been done, is being done, and probably will continue to be done in the future under various guises. The implications for society, especially the criminal justice system, need to be examined.

The authors cite the past fiasco of the "XYY" studies and how like situations should be avoided in the future. They realize that DNA fingerprinting is being utilized in criminal court cases throughout the United States. This test has limitations, like all biological tests, yet many lawyers are unaware this test is not 100% accurate. The authors also address other potential scenarios of misinterpretation of genetic testing that need to be examined. This includes the results of genetic testing for predisposition to various diseases and possible aggressive and/or criminal behavior. The authors stress the importance of such discussions now, before more tests are available. This is preferable to waiting until the tests are utilized, then trying to negate possible damage from discrimination and stigmatization.

The authors propose a multi-disciplinary conference to discuss the above topics and other related subjects. They have brought together well-recognized experts in the fields of law, medicine, genetics, psychology and sociology, as well as historians and philosophers to evaluate the role, if any, of such research in the criminal justice system.



Page Two (cont'd)  
July 17, 1992  
Bernadine Healy, M.D.

This subject is an extremely critical one and needs to be discussed "yesterday". The role of the ELSI program of NCHGR is to explore the implications of this type of research and, hopefully, to educate the public on such subjects. This, and other situations, will arise in the future where the press and others will misinterpret the subject matter. In this case, the title of this proposal, while accurate, is potentially misleading. It is a sad reflection on our society that we see a title like this and immediately expect the worse. However, it also demonstrates that we, who are involved in grant reviews, need not only to look at the scientific content of grant applications, but also need to evaluate how titles and information may be exploited inadvertently or purposely by others. In this regard, I believe the brochure needs to be modified.

In summary, the language of science tends to be cold, to be dispassionate and to present both sides of an issue or controversy. Because of this, sentences in the proposal can often be misinterpreted if used out of context. I am disappointed the press, television, or whomever has latched onto a few key words and misinterpreted the reasons behind the conference.

However, if this situation is mishandled with the academic community and the author of the grant, such important discussions will not occur. Then we will have research and testing, no discussion before utilization, and the potential for a "Nazi-like" society.

Since I do not know specifically who is voicing concern about what specific details, it is difficult to address the concerns.

However, if the conference is canceled, it sends a message to the opponents of such discussion, that their interpretations are the interpretation of the grant review panel.

At the least, I would recommend a conference call with the chair of the review panel, key participants in the review panel, and key administrative and/or staff of NIH. Perhaps the brochure can be re-vamped with the aid of the principal investigator and the above participants.

Page Three (cont'd)  
July 17, 1992  
Bernadine Healy, M.d.

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If a conference call is not adequate or sufficient, an in-person meeting may be the next alternative to resolve this issue. Please let me know your decision regarding these issues and if I can participate further.

Sincerely,



Nancy L. Fisher, M.D., M.P.H.  
Medical Geneticist

NLF:cld

(c:\epj\correspondence\healy.b)

cc: NIH File  
Outgoing Correspondence File



---

National Institutes of Health  
National Center for Human  
Genome Research  
Bethesda, Maryland 20892

Building 38A, Room 617  
(301) 402-0911  
(301) 480-2770 FAX

July 16, 1992

FACT SHEET: ELSI Grant R13 HG00703-01

Biomedical researchers are increasingly looking to the gene to help explain the biological underpinnings of disease. In the past several years, these studies have expanded to include examination of the complex processes that influence human behaviors. These studies have begun to shed light on the biological roots of some devastating psychiatric illnesses, such as schizophrenia, manic-depressive illness, and alcoholism, offering hope for better treatments.

But such studies also raise the question of how genes might contribute to human behavior in general. What are the relative contributions of biological and environmental influences? Are those influences the same for all human behaviors? Scientists hope that by teasing out the genetic contributions to human behavior, they can gain better insights into the role environmental factors play in influencing behavior.

The search for biological factors that may contribute, along with social and economic conditions, to violent human behavior is one of the most controversial pursuits in human genetics research. The scientific soundness of such studies, assumptions on which they are based, and the social implications of the findings are being vigorously debated. To examine these questions, the University of Maryland's Institute for Philosophy and Public Policy is hosting a conference October 9-11, 1992, on the College Park campus. The conference is

supported by a grant from the National Center for Human Genome Research's (NCHGR) Ethical Legal and Social Implications (ELSI) Branch. NCHGR is the component of the National Institutes of Health charged with overseeing its role in the Human Genome Project.

The University of Maryland conference is part of a broad and diverse series of NCHGR-supported projects to identify and publicly address the ethical and social issues raised by new advances in genetics research. Participants will include experts with a variety of views in the fields of law, sociology, behavior research, and philosophy. The conference will address the most fundamental scientific, ethical, and policy issues raised by this research: Do genetic explanations of criminal behavior undermine or refine environmental explanations? Will genetics research obscure or focus the search for social and environmental causes of crime? Can genetics explain socially constructed categories of behavior? How should claims of genetic influence and genetic predisposition be viewed by the criminal justice system? How might such claims affect public perceptions and broader social policies?

The goals of the Human Genome Project are to identify the estimated 100,000 genes on human chromosomes and to read the complete genetic text contained in DNA. Tools developed by the project will give researchers unprecedented powers to find and analyze genes. Genome project founders recognized early on that a crucial component of the program would be to foresee potential personal and social consequences of generating more-sophisticated genetic information. The ELSI program was established to anticipate problems brought about by the use of genetics technologies and offer policy options to deal with them. The ELSI budget is currently \$5 million, just over 5 percent of the NCHGR research budget.

# # # #



National Institutes of Health  
National Center for Human  
Genome Research  
Bethesda, Maryland 20892

Building 38A, Room 617  
(301) 402-0911

July 16, 1992

Via Fax: 202-690-6603

Mr. Alex Ross  
Health Planning Office  
Office of the Assistant  
Secretary for Health  
Washington, DC

Dear Mr. Ross:

Here is the information you requested concerning the Ethical, Legal, and Social Implications (ELSI) Branch of the National Center for Human Genome Research (NCHGR). The following documents are included in this fax:

1. The roster of the study section that reviewed David Wasserman's application for the "Genetic Factors in Crime: Findings, Uses, and Implications" conference.
2. A list of other conference grants funded by the ELSI program.
3. The program announcement stating the NCHGR's interest in receiving applications to the ELSI program.
4. The roster of the ELSI Working Group members and a description of their activities and interests.
5. A description of the activities of the ELSI Working Group and the ELSI Program.
6. Pages from the "Genetic Factors in Crime: Findings, Uses, and Implications" conference proposal describing the program content and expertise of the participants.

If you need additional information, please call me at the National Center for Human Genome Research (301) 402-0911.

Sincerely,

Elinor J. Langfelder  
Program Analyst  
Ethical, Legal, and Social Implications

CHAIRPERSON

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Buffalo

Chief

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Genetic Counselor/Instructor

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Writer/Producer

Goodchild Productions

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School of Law

Albuquerque, NM 87131

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Professor and Chair

Department of Health Behavior

and Health Education

School of Public Health

University of North Carolina

Chapel Hill, NC 27599

THOMASMA, David C., Ph.D.

Fr. Michael I. English, S.J.,

Professor of Medical Ethics

Director of Medical Humanities

Stritch School of Medicine

Loyola University

Maywood, IL 60153

WATSON, Bracie, Ph.D.  
Geneticist  
DNA Diagnostics Laboratory  
Department of Microbiology  
University of Alabama  
School of Medicine  
Birmingham, AL 35233

SCIENTIFIC REVIEW ADMINISTRATOR

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Genome Study Section  
Division of Research Grants  
National Institutes of Health  
Bethesda, MD 20892

GRANTS ASSISTANT

MYERS, Terri  
Genome Study Section  
Division of Research Grants  
National Institutes of Health  
Bethesda, MD 20892

Consultants are required to absent themselves from the room during the review of any application if their presence would constitute or appear to constitute a conflict of interest.

**Conference Grants (R13) funded by the National Center for Human Genome Research  
Program on Ethical, Legal, and Social Implications**

Doris Goldstein, Kennedy Institute of Ethics, Georgetown Univ.  
"Strategies for Documentation of Research on the Human Genome"

Award date: 9/11/90

Conference date: December 10, 1990, Washington, DC.

(Y2 HG001101 Co-funded with NSF)

FY 1990 Funding: \$5,500

Outcome:

Consensus that a committee to issue recommendations about documenting human genome research should be formed.

Sherman Elias, University of Tennessee, and George Annas, Boston University  
"Human Genome Workshop: Ethics, Law and Social Policy"

Award date: 9/26/90

Conference date: Jan. 24-25, 1991, Bethesda, MD.

(1R13 HG00421-01)

FY 1990 Funding: \$37,827

Outcome:

Consensus Report on ELSI research priorities, forthcoming in Politics and the Life Sciences

Annas, G.J. & Elias, S., eds., Gene Mapping: Using Law and Ethics as Guides, Oxford University Press, New York, (Aug. 1992) (book based largely on papers presented and discussed at the workshop)

Mark Rothstein, University of Houston (1 R13 HG00160-01).

"Legal and Ethical Issues Raised by the Human Genome Project"

Award date:

Conference date: March 7-9, 1991, Houston, TX.

FY 1990 Funding: \$20,314

FY 1991 Funding: \$55,771

Outcome:

Conference report to be published in April 1992 in a special issue of the *University of Houston Law Review*

Proceedings published by University of Houston Health Law and Policy Institute



Daniel Callahan, The Hastings Center

"The Genetic Prism: Understanding Health and Responsibility"

Award date: 9/26/90

Conference date: April 8-9, 1991, Berkeley, CA

(1 R13 HG00432-01)

FY 1990 Funding: \$25,400

Outcome:

Conference proceedings to be published in a special supplement of the *Hastings Center Report*

Arthur Caplan, Univ. Minnesota, Center for Biomedical Ethics

"Ethics, Values, Professional Responsibilities"

Award date: 9/26/90

Conference date: April 19-20, 1991, Minneapolis, MN

(1 R13 HG00433-01)

FY 1990 Funding: \$35,116

Outcome:

Summary Report on norms of genetic counseling to be published in the *Journal of Genetic Counseling*

Conference Volume "Prescribing Our Future: Ethical Challenges in Genetic Counseling" will be published by Aldine de Gruyter.

Daniel Wikler, University of Wisconsin (1 R13 HG00431-01)

"Human Genome Research in an Interdependent World"

Award date: 9/26/90

Conference date: June 2-4, 1991, Bethesda, MD.

FY 1990 Funding: \$97,240

FY 1991 Funding: \$14,011

Outcome:

Consensus Report including a proposal for Coordination of International ELSI issues by HUGO

Albert Teich, AAAS

"Ethical and Legal Implications of Genetic Testing"

Award date: 9/25/90

Conference dates: March 13-15, 1992, Charleston, SC

June 18-20, 1992, Los Alamos, NM

1 R13 HG00119-01

FY 1990 Funding: \$118,097

FY 1991 Funding: \$69,974

Outcome:

Conference proceedings: *The Genome, Ethics, and the Law: Issues in Genetic Testing*, (AAAS publication Number 92-115)

Dennis Karjala, Arizona State University

"A Legal Research Agenda for the Human Genome Initiative"

Award date: 12/28/90

Conference date: March 14-16, 1991, May 18-20, 1991, Tempe, AZ

1 R13 HG00265-01

FY 1991 Funding: \$91,318

Outcome:

Conference proceedings published in a special issue of *Jurimetrics*, Winter 1992.

Summary of project and issues raised to be published in ASU Research Condensed version being prepared for submission to scientific journals

Results to be presented at the Gruter Conference June 21-25, 1992, Squaw Valley, California.

Susann Wilkinson, Georgetown University

"Biotechnology and the Diagnosis of Genetic Disease"

Award date: 5/16/91

Conference date: April 18-20, 1991, Alexandria, VA

(Co-Funded with FDA)

FY 1991 Funding: \$35,000

Outcome:

Consensus Report on FDA's role in regulation of genetic technology

Deborah Eunpu, Developmental Medicine and Genetics, Albert Einstein Medical Center, Philadelphia, PA

"The Human Genome Project: a Public Forum"

Award date: 9/17/91

Project Period: Sept. 14-15, 1991

(1 R01 HG00401-01)

FY 1991 Funding: \$21,679

R. Steven Brown, Science policy, The Council of State Governments, Lexington, KY.

"State Governments and the Human Genome Project"

Award date: 4/5/91

Project Period: 4/10/91-9/30/92 (series of conferences)

(1 R13 HG00270-01)

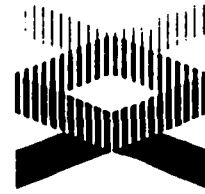
FY 1991 Funding: \$136,014

Doris Zallen, Humanities, Virginia Polytechnic Institute,  
Blacksburg, VA  
"The Human Genome Project: A Choices and Challenges Forum:  
Award date: 3/20/92  
Conference date: April 4, 1992  
(1R13 HG00584-01)  
FY 1992 Funding: \$33,919

Sheldon W. Samuels, Workplace Health Fund, Washington, DC  
"Labor Conference on the Workplace and the Human Genome"  
Award date: 9/17/91  
Conference Date: May 29-31, 1992  
(1 R13 HG00449-01)  
FY 1991 Funding: \$69,327

Barbara Bowles Biesecker, Human Genome Center, University of Michigan  
"A Conference on Human Genome Research Implications"  
Conference Date: June 5-7, 1992  
(1 R13 HG00638-01)  
FY 1992 Funding: \$206,513

David Wasserman, Institute for Philosophy and Public Policy, University of Maryland  
"Genetic Factors in Crime: Findings, Uses, and Implications"  
Conference Date: October 9-11, 1992  
(1R13 HG00703-01)  
FY 1992 Funding: \$78,478



National Center  
for Human  
Genome Research

## **PROGRAM ANNOUNCEMENT**

# **ETHICAL, LEGAL AND SOCIAL IMPLICATIONS OF HUMAN GENOME RESEARCH**

National Center for Human Genome Research

Application Receipt Dates: October 1, February 1, June 1

This Program Announcement supersedes the one which appeared in the January 26, 1990, issue of the NIH Guide to Grants and Contracts, (Vol. 19, No. 4) and restates the interest of the National Center for Human Genome Research (NCHGR), National Institutes of Health (NIH), in receiving applications for research grants, education grants, and conference grants addressing ethical, legal, and social issues that may arise from the application of knowledge gained as a result of the human genome research. Applications for cross-disciplinary post-doctoral training are also being sought.

### **Background**

The NIH is currently engaged, along with several other federal, private, and international organizations, in a research program known as the Human Genome Project. This program is designed to characterize the human genome and the genomes of selected model organisms. It has several interrelated goals: the construction of high resolution genetic linkage maps; the development of physical maps of the human genome and the genomes of selected model organisms; the determination of the complete nucleotide sequence of human DNA and the DNA of several model organisms; the development of the capability for collecting, storing, distributing, and analyzing the data and materials produced; and the development of appropriate new technologies necessary to achieve these objectives. The information that will be obtained as a result of the genome project will be a resource for studies of gene structure and function and will promote research into the genetic aspects of human disease.

The capabilities that arise out of the Human Genome Project are also expected to have a profound impact on individuals and society. Over 4,000 known inherited disorders have been identified. Some cause disease before birth, or shortly thereafter, while others are

observed only in adulthood. Mapping the human genome will increase our ability to predict, understand, and eventually prevent or cure human diseases. However, knowing the entire sequence of the human genome will also raise questions about how this information should be used. There are numerous social, legal, and ethical implications of this endeavor. To anticipate the impact of the Human Genome Project, the NIH will give high priority to studies that address these issues and develop options for policies or programs that minimize the possibilities of adverse impact. The NIH is also interested in improving public education and understanding of the issues and stimulating broad discussion among the general public, professionals, and policy makers, with the goal that the information generated be of maximum benefit to individuals and society.

## Research Scope

This program announcement emphasizes the ongoing commitment of the NIH to support activities that focus on anticipating issues arising from the application of the results of the Human Genome Project and on proposing solutions that will forestall adverse effects.

In order to accomplish these objectives, support will be provided through research grants, conference grants, education grants, and individual post-doctoral fellowships for projects designed to address a range of ethical, social, and legal issues. Areas of special interest include, but are not limited to, the following topics:

1. Questions of fairness in the use of genetic information with respect to:
  - insurance
  - employment
  - the criminal justice system
  - the educational system
  - adoptions
  - the military
  - other areas to be identified.
2. The impact of genetic information on the individual, including questions of:
  - stigmatization
  - ostracism
  - labelling
  - individual psychological responses.
3. The privacy and confidentiality of genetic information, including questions of:
  - ownership and control of genetic information
  - consent to disclosure and use of genetic information.
4. Issues raised by the impact of the Human Genome Project on genetic counseling in the following areas:
  - pre-natal testing
  - pre-symptomatic testing

- carrier status testing
  - testing when there is no therapeutic remedy available
  - counseling and testing for polygenic disorders
  - population screening versus testing.
5. Issues raised by reproductive decisions influenced by genetic information, including questions of:
    - the effect of genetic information on options available
    - the use of genetic information in the decision-making process.
  6. Issues raised by the introduction of increased genetic information into mainstream medical practice, including questions of:
    - professional standards of care and quality control in acquiring and using genetic information
    - the qualifications and training of health professionals involved in genetic testing and counseling
    - impact on the physician-patient relationship
  7. The uses and misuses of genetics in the past and their relevance to the current situation, e.g.:
    - the eugenics movement in the U.S. and abroad
    - problems arising from screening for sickle-cell trait and other recent examples in which screening or testing sometimes achieved unintended and unwanted outcomes
    - the misuse of behavioral genetics to advance eugenics or prejudicial stereotypes.
  8. Questions raised by the commercialization of the products from the Human Genome Project in the following areas:
    - intellectual property rights (patents, copyrights, and trade secrets)
    - property rights
    - impact on scientific collaboration and candor
    - accessibility of data and materials.
  9. Conceptual and philosophical implications raised by the Human Genome Project such as its implications for:
    - the concepts of personal identity and responsibility
    - the problems of determinism and reductionism
    - the concepts of health and disease [particularly in view of the high rate of human genetic variability and the large numbers of people who will be found to have genetic vulnerabilities].

Most of these topics can best be addressed through scholarly research or conferences. Support for conferences will be limited to those that are highly focussed and produce a specific product, such as recommendations or policy options. Research should be appropriate to the nature of the projects proposed and the disciplines involved, but priority

will be given to studies that address the normative problems of social policy, professional ethics, and jurisprudence raised by the topics above. Thus, projects that use the interpretive methods traditional to humanities, law, and the social sciences are particularly encouraged.

It is essential that applicants address the full range of views on each issue they select to investigate in a responsible, scholarly, and balanced manner, with the goal of advancing scholarship, achieving better understanding, or working towards consensus or useful recommendations. Collaborative projects between geneticists and ethicists, legal scholars, educators, or social scientists are encouraged.

### **Individual Post-doctoral Fellowships**

An important aspect of the program is to train individuals who have the knowledge and skills to address the research topics listed above in a comprehensive and thorough manner. For this reason, fellowships will be provided to scientists trained in biomedical disciplines relevant to the human genome project to pursue study in ethics, law, or other topics that will enable these scientists to contribute to studies of the ethical, legal, or social implications of the genome project. Conversely, individuals with doctoral degrees in disciplines traditional to the humanities and social sciences can receive support for post-doctoral studies in human genetics and genome research in order to enhance their abilities to address problems related to the Human Genome Project. Support for fellowships will be provided through National Research Service Awards. The training to be supported must be research-oriented training. Studies leading to a professional degree will not be eligible for funding under this mechanism. Additional details about the policies and procedures governing these post-doctoral fellowships can be found in the NIH Guide to Grants and Contracts, Vol. 20, No. 46, December 12, 1991. Single copies are available from this office.

### **Mechanism of Support**

Support for this program will be through several mechanisms--research grants (R01), conference grants (R13), education grants (R25), and individual post-doctoral fellowships (F32) and senior fellowships (F33).

### **Application Review**

Applications received in response to this announcement will be reviewed by a special study section selected for expertise in the appropriate areas of ethics, law, medicine, genetics, social science, and public education. Applicants are strongly urged to contact NIH staff to discuss their plans before submitting an application.

Criteria for evaluating the applications will include:

- o Potential for producing new knowledge or understanding;
- o Potential impact of the proposed project to provide solutions to critical issues;
- o Balance and breadth of approach;
- o Originality of the project (i.e., does not duplicate other efforts or approaches);
- o Potential of the proposed project in terms of scholarly or lay audience reached;
- o Experience and expertise of the applicants.

A handbook containing more detailed information about the review process and advice on how to write the proposal is available from the National Center for Human Genome Research.

### **Method of Applying**

Applications should be submitted on the new form PHS 398 (Rev. 9/91). Application kits are available at most institutional business offices and from:

Office of Grants Inquiries  
Division of Research Grants  
Westwood Building, Room 449  
National Institutes of Health  
Bethesda, Maryland 20892

Applications for research grants and conference grants will be accepted in accordance with the usual NIH receipt dates for new applications--October 1, February 1, and June 1; funding decisions will be made approximately 9 months after receipt of applications. Applications for individual post-doctoral fellowships will be accepted September 10, January 10, and May 10; funding decisions will be made approximately 6 months after receipt of applications.

It is essential that applicants type "Ethical, Legal and Social Implications of the Human Genome Initiative," in Item 2 on the face page of the application form. The conventional presentation for grant applications should be utilized (see instructions in application kit.)

The original and six copies of the application should be submitted to:

Application Receipt Office  
Division of Research Grants  
Westwood Building, Room 240  
National Institutes of Health  
Bethesda, Maryland 20892



Applications that deal with a specific medical condition may be assigned to the NIH Institute responsible for that condition with secondary assignment to NCHGR. Funding decisions will be based on recommendations of the initial review group and a National Advisory Council regarding scientific merit and program relevance, respectively, and on the availability of funds.

For additional information, please contact:

Eric T. Juengst, Ph.D.

Program Director

Ethical, Legal and Social Implications Program

National Center for Human Genome Research

Building 38A, Room 617

National Institutes of Health

Bethesda, Maryland 20892



April 15, 1992

**Activities of the NIH-DOE Joint Working Group on Ethical, Legal, and Social  
Implications of Human Genome Research  
July 1992**

**Introduction**

The mission of the NIH-DOE Working Group on the Ethical, Legal, and Social Implications (ELSI) of Human Genome Research is to:

- anticipate and address the implications for individuals and society of mapping and sequencing the human genome;
- examine the ethical, legal, and social consequences of mapping and sequencing the human genome;
- stimulate public discussion of the issues;
- develop policy options to assure that the information is used for the benefit of the individual and society.\*

Toward these goals, the ELSI Working Group delineated four high priority areas for program activities by NIH and DOE:

1. research on issues of quality and access in the use of genetic tests
2. research on the fair use of genetic information by employers and insurers.
3. research on privacy issues involving genetic information
4. public and professional education

These four areas served as the basis for the NCHGR report which was submitted to Congress, in January 1991, entitled, "The Ethical, Legal, and Social Implications of Human Genome Research: Preparing for the Responsible Use of New Genetic Knowledge." This memo describes the ELSI Working Group's 1991 activities in each of the high-priority areas.

**Issues of quality and access in the use of genetic tests**

1. **Studies of CF testing and counseling funded.** Eight studies were funded from applications submitted to the NIH Request for Applications (RFA# HG-91-01) entitled "Studies of Testing and Counseling for Cystic Fibrosis Mutations."

Three components of the NIH--the NCHGR, the National Institute of Child Health and Human Development, and the National Center for Nursing Research--have launched a three-year research initiative to define the best methods for educating and counseling individuals who want to be tested for CF mutations. Seven research teams across the country will conduct eight studies to address issues in testing, education, and counseling for the CF mutations. The NCHGR has taken the lead role in supporting these studies. In addition, in order to facilitate communication among the research teams, the principal investigators will meet regularly as a consortium.

\*Understanding our Genetic Inheritance. The U.S. Genome Project: The First Five Years FY 1991-1995.

**2. NAS/IOM study.** The NIH and DOE have co-funded a study by the National Academy of Sciences/Institute of Medicine, "Predicting Future Disease: Issues in the Development, Application, and Use of Tests for Genetic Disorders." This study is aimed at producing professional recommendations for the integration of genetic services into mainstream medical practice. The first, agenda-setting, meeting of the study panel took place on July 23-24, 1991. The second meeting, scheduled for February 12-13, 1991, will focus on issues concerning the quality control of laboratory practices.

**3. White paper commissioned.** The ELSI Working Group commissioned a white paper to provide an expert review of the state of research in this priority area, "Cystic Fibrosis Heterozygote Detection: The Introduction of Genetic Testing into Clinical Practice" (Benjamin Wilfond, M.D. and Norman Fost, M.D., University of Wisconsin).

### **Fairness in the use of genetic testing**

**1. Insurance Task Force.** The ELSI Working Group Insurance Task Force, (ITF) co-chaired by ELSI Working Group members Tom Murray and Jon Beckwith, met in May 1991, in Cleveland, OH. The Task force is comprised of representatives from the Insurance industry, corporate benefit plans, consumer and health voluntary groups, and scholars actively researching insurance issues. The group developed a plan of action for developing guidelines for insurance policy by 1993.

The second meeting of the ELSI Insurance Task Force was held in Washington, D.C., where the ITF met with insurance underwriters and actuaries, to learn about the use of genetic data in risk assessment procedures. Before the next meeting, subgroups of the ITF will: (1) devise a mechanism in which the policy implications of existing discrimination cases can be examined, and (2) draft a set of principles concerning the use of genetic tests in insurance underwriting and coverage practices. The next meeting is scheduled for March 23-24 in Boston. The group plans to meet with representatives of the Medical Information Bureau, a database used by insurance companies.

The third meeting of the ELSI Insurance Task Force was held in Bethesda, MD, on March 23-24 (the meeting site was changed from Boston due to restrictions in the NCHGR travel budget). The ITF met with staff of State Insurance Commissioners offices, as well as experts in employment discrimination law and self insured corporate benefit plans. A number of issues were discussed which will form core principles to be addressed in the Insurance Task Force's official report, slated for May of 1993. In addition, the ITF subgroup chartered to address alleged cases of insurance discrimination presented a series of background papers. These papers recognize work that has already been done in this area and lay the groundwork for the tasks of this subcommittee. The next meeting of the Insurance Task Force will take place on May 31-June 1, 1992.

The Task force met again on May 31-June 1. The meeting was devoted to creating an outline of the final report. A subcommittee was formed to research and report on the flow of genetic information from tests to records to insurance companies, and another is

investigating the nature of adverse selection. Adverse selection happens when insurance applicants know they will become ill from a genetic disorder, then conceal the genetic test results and purchase additional insurance at a low premium. The insurance companies will pay out claims to these people at a higher than expected rate. Fear of adverse selection is one of the major reasons cited by the insurance industry for reserving the right to access the results of genetic tests of its applicants. Reports of these subcommittees will be heard at the next meeting of the Task Force, which will be held in San Francisco, CA, November 9-10.

**2. White paper commissioned.** The ELSI Working Group commissioned a white paper to delineate policy options in the area of insurance and employment testing, "The Ethical, Legal, and Social Issues Concerning the Use of Genetic Tests by Insurers: Toward the Development of Appropriate Public Policy" (Nancy Kass, Sc.D., Johns Hopkins University)

**3. Statement on Americans With Disabilities Act developed.** In a statement to the EEOC, the members of the ELSI Working Group identified three areas in which significant changes to the EEOC regulations should be made to improve the ADA's protections against genetic discrimination, and recommended the following amendments to the regulations:

- a. discriminatory actions based on an individual's genotype, including the possibility of having affected children, should be covered by the ADA.
- b. post-offer, employment entrance medical examinations should be limited to assessing job-related physical and mental conditions.
- c. in order to limit access by employers to genetic information in medical records and health insurance claims:
  1. an employer should be permitted to require that an employee or applicant authorize his or her health care to respond to specific, job-related questions, rather than sign a blanket release form.
  2. rule-making proceedings should be initiated to determine the most effective way of protecting the privacy of health insurance claims. One option is for each employee to have a separate medical claims number and submit claims by number only.

These recommendations were presented for discussion and endorsed by the NIH-DOE Program Advisory Committee on the Human Genome on June 25, 1991. An EEOC representative responded to these concerns, saying that non-job related testing was in fact legal as long as the results of such tests are not used for discriminatory purposes. They also indicated that the ADA does not protect the privacy of medical information. The Working Group is awaiting further clarification of other aspects of the EEOC response.

## **Privacy issues involving genetic testing**

- 1. Privacy panel.** At the request of the Working Group members, a panel meeting of experts convened in Boston on June 28, 1991, to discuss policy approaches to genetic privacy. The Working Group needed to become better informed about the implications of the Human Genome Privacy Act, which was re-introduced into the House by Representative Conyers.
- 2. White paper commissioned.** The Working Group commissioned a paper on the issues of privacy and discrimination, "Genetic Discrimination: Use of Genomic Information to Exclude Persons from Employment, Insurance, and Access to Health Care" (Larry Gostin, J.D., Harvard University)
- 3. ELSI Working Group Workshop.** The September ELSI Working Group Workshop focused on privacy of genetic information, and continued the discussion of issues raised at the June privacy meeting. This discussion included the consumer perspective, as well as privacy of stored biological, computer files, and research data. An initiative on privacy, was chartered to look in depth at privacy protections for genetic data.
- 4. Congressional hearing on privacy.** The House Committee on Government Operations held a hearing on October 17 to hear testimony on the privacy of genetic information. Bernadine Healy, James Watson, David Galas, and Nancy Wexler were among the panelists who advocated the need for preserving the right to privacy of genetic information while preventing discrimination against those who choose not to keep their genetic make-up private.

## **Public and Professional Education**

- 1. Outreach meeting held.** Leaders of voluntary health organizations and genetic disease support groups were addressed by members of the scientific community and the ELSI Working Group at the NCHGR's first public outreach meeting, in January, 1991. The purpose of the meeting was to encourage these groups to participate in the on-going discussion of the ethical, legal, and social implications of the Human Genome Project. The meeting closed with a request for further discussion of educational issues.
- 2. Education Consultation.** As a follow-up to the January Outreach meeting, consultants who have demonstrated expertise in K-12, undergraduate, graduate, professional, and/or public education were invited to an NCHGR Education Consultation, to discuss the state of genetics education in the United States. Plans to work with Alliance of Genetic Support Groups, CORN, and the National Issues Forum, to promote public education were initiated.
- 3. Public Forum.** The ELSI working group held its first public forum in Iowa City, IA on April 21, 1992. University of Iowa faculty gave background information on genetics and the significance of Human Genome Project, emphasizing its implications for health

and health policy. Representatives of families affected by genetic disorders, state genetics coordinators, clinical genetics services providers, and clergy testified on issues related to delivery of and access to genetic services, including ethno-cultural sensitivity and personnel numbers and education needs; the need for protection of the privacy of genetic information; and the risk of discrimination on the basis of genotype. Many of those who testified stressed the importance of involving families affected by genetic disorders in the ELSI program activities. The members of the working group were impressed by the breadth and depth of the testimony and discussion that followed. Copies of the written testimony are available on request from NCHGR.



**September 1991      ELSI Working Group Workshop, Bethesda, MD  
"Privacy of Genetic Information"**

**ELSI Working Group Accomplishments:**

- Privacy Task Force chartered
- plan of action for continued discussion of privacy

**December 1991      Meeting of the ELSI Insurance Task Force  
Washington, DC**

**ELSI Working Group Subcommittee's Accomplishments:**

- became informed about the use of genetic data by insurance companies
- plan to draft set of principals by next meeting
- plan to examine existing cases of genetic discrimination

**February 1992      ELSI Working Group Workshop, Bethesda, MD  
"Priorities for Program Initiatives"**

**ELSI Working Group Accomplishments:**

- advised ELSI program staff to address four priority areas: the psychosocial impact of prenatal diagnosis, testing and counseling for the p53 mutation, ethical issues involved in pedigree research, and public and professional education.
- set April 21 as the date for the ELSI public forum in Iowa City, IA
- set September 14-16, 1992, as the date for a workshop of all NCHGR and DOE ELSI grantees.

**March 1992      Meeting of the ELSI Insurance Task Force  
Bethesda, MD**

**ELSI Working Group Subcommittee's Accomplishments:**

- became informed about legislative and regulatory issues concerning genetic testing and insurance
- drafted set of core principals for further discussion and refinement
- wrote set of background papers on past work in this area, existing policy statements, and industry positions on genetic testing.



**April 1992**

**ELSI Public Forum  
Iowa City, IA**

**ELSI Working Group Accomplishments:**

- heard testimony from persons affected by the introduction of genetic tests into clinical practice
- drafted set of core principals for further discussion and refinement
- wrote set of background papers on past work in this area, existing policy statements, and industry positions on genetic testing.

**May 1992**

**Meeting of the ELSI Insurance Task Force  
Bethesda, MD**

**ELSI Working Group Subcommittee's Accomplishments:**

- drafted outline of final report
- assigned subgroups to gather information on adverse selection and the flow of genetic information between genetic tests, medical records, and insurance companies

**NIH-DOE Joint Working Group on  
Ethical, Legal, and Social Implications of Human Genome Research**

**Roster**

**Chairperson:**

**Nancy Wexler, Ph.D.**  
Hereditary Disease Foundation  
and  
Department of Neurology and Psychiatry  
College of Physicians and Surgeons  
Columbia University  
722 West 168th St. Box 58  
New York, NY 10032

**Jonathan Beckwith, Ph.D.**  
Department of Microbiology  
and Molecular Genetics  
Harvard Medical School  
200 Longwood Avenue

664

**Victor McKusick, M.D.**  
Division of Medical Genetics  
Johns Hopkins Hospital  
600 N. Wolfe Street  
Blalock 10007  
Baltimore, MD 21205

**Robert Cook-Deegan, M.D.**  
Division of Biobehavioral  
Sciences and Mental Disorders  
Institute of Medicine  
National Academy of Sciences  
2101 Constitution Ave., NW  
Washington, D.C. 20418

**Robert F. Murray, Jr. M.D.**  
Department of Pediatrics, Box 75  
Howard University College of Medicine  
520 W Street, NW  
Washington, DC 20059

**Patricia King, J.D.**  
Georgetown University Law Center  
600 New Jersey Avenue, N.W.  
Washington, DC 20001

**Thomas H. Murray, Ph.D.**  
Center for Biomedical Ethics  
School of Medicine  
Case Western Reserve University  
2119 Abington Road  
Cleveland, OH 44106

## Contributors to the Report on Ethical, Legal, and Social Issues

**Jonathan R. Beckwith** is a bacterial geneticist interested in genetic screening. For more than 20 years, he has been interested in and concerned about the long-range implications of genetics and behavior and genetics and intelligence quotient.

**Robert Cook-Deegan** is a clinician whose interest in genetics dates back to his research on Alzheimer's Disease. While on an Office for Technology Assessment fellowship, he prepared two reports on human gene therapy and public policy related to the human genome project. Dr. Cook-Deegan is currently writing a book on how the Human Genome Initiative got started in the United States.

**Patricia King** is an attorney and academician whose legal career has been in civil rights law. She has served on the National Committee for Protection of Human Subjects, the Recombinant DNA Advisory Committee, and the Presidential Committee on Ethics. Ms. King is a Fellow of the Hastings Center and is interested in genetics and how it affects minorities.

**Victor A. McKusick** is an internationally recognized geneticist who has been active in human genetics research for over 40 years. More than any other person, he has been responsible over the years for collecting data on inherited diseases. Since 1973, he has collected and coordinated data on the human gene map, which in 1988 included 2,000 genes.

**Robert F. Murray, Jr.** is a clinical researcher who directs a clinical genetics program in sickle-cell disease. He became involved initially with the ethical aspects of screening for sickle-cell disease. Dr. Murray is concerned about individuals who want to plan their destiny based on new technologies emanating from genetics research.

**Thomas H. Murray** is a social psychologist who has written extensively about genetic screening in the work place. He has undertaken fellowships with an emphasis on humanities at Yale University and The Hastings Center. Dr. Murray was recently elected a Fellow of The Hastings Center and is currently co-authoring a publication with a geneticist for the British Medical Association.

**Nancy S. Wexler** is a clinical psychologist and a researcher. Her mother died of Huntington's Disease and she is a potential consumer of the information generated by the Human Genome Initiative. Many of her current efforts are to get individuals, interest groups, and the federal government to anticipate how information generated from the Human Genome Initiative can be used maximally to benefit the individual.



June 29, 1992 3 27 PM '92

National Institutes of Health  
Bethesda, Maryland 20892

David T. Wasserman, J.D.  
Research Scholar  
University of Maryland  
Room 0123 Woods Hall  
College Park, MD 20742

Dear Dr. Wasserman:

Del Walters, a reporter for WJLA-TV, has requested a copy of your grant application #1R13 HG00703-01 titled Genetic Factors in Crime: Findings, Uses & Implications. Enclosed is a copy of the request. The Freedom of Information Act requires the release of records held by the Government, except for any portions that are permitted to be withheld under various exemptions recognized by the Act.

Consistent with the enclosed general guidance, please advise us of any portions of the records that you believe should be withheld. You may find it convenient to send us an extra copy of the material, indicating the portions that you recommend be withheld. We are required to separate out information that the FOIA requires us to release, even though other parts of a document may be withheld. The general guidance will help you identify such portions.

So that we may comply with the requirement to respond promptly, please let us have your reply by July 10, 1992. We should like a response from you even if you find that no material should be withheld. If that is the case, you may indicate your approval for release in the space provided below and return this letter to me at the address provided. We shall interpret a failure to reply as meaning that you have no objection to release of the application and will plan to release it at the close of business on July 10, 1992. If you wish to call, my number is (301) 402-0733.

Thank you for your cooperation.

Sincerely,

Alice H. Thomas  
Freedom of Information Coordinator  
National Center for Human Genome Research

Enclosures:

APPROVAL FOR RELEASE:

David T. Wasserman  
NAME

7-1-92  
DATE

No material withheld.



National Institutes of Health  
National Center for Human  
Genome Research  
Bethesda, Maryland 20892

Building 36A, Room 605  
(301) 496-0844  
(301) 402-0837 (Fax)

June 24, 1992

**TO:** Ms. Anne Thomas  
Acting Director of Communications

**FROM:** Deputy Director, NCHGR

**SUBJECT:** Conference on Genetics Factors in Crime

Here is information about the conference on genetics factors in crime. I have reviewed the application and find the conference quite appropriate for the ELSI program.

A handwritten signature in cursive script that reads "Elke".

Elke Jordan, Ph.D.

Attachment

cc:  
Dr. Michael Gottesman



June 24, 1992

National Institutes of Health  
Bethesda, Maryland 20892

TO: Deputy Director, NCHGR

FROM: Acting Chief, ELSI Branch

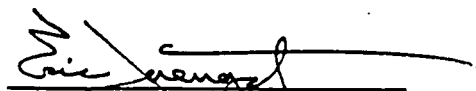
RE: R13-HG00703-01 "Genetic Factors in Crime: Findings, Uses, and Implications"

R13-HG00703-01 is a conference grant supporting a meeting designed to address and clarify the methodological, legal and philosophical issues raised by research on genetic factors in violent and criminal behavior.

Studies of genetic factors in criminal behavior are among the most controversial areas of research in human genetics. The scientific reliability of such research, its philosophical assumptions, and its social implications for the criminal justice system have been the subjects of long-standing debate within and beyond biomedicine. This conference, organized by the Institute for Philosophy and Public Policy at the University of Maryland, will review historical trends and discuss recent findings in criminology, behavioral genetics and forensic psychiatry, and delineate the ethical and social issues involved in utilizing those findings in criminal investigation and adjudication.

The goal of this conference is to clarify the prospects and limits of behavioral genetics research in these areas, and to evaluate what role, if any, such research results should have in the criminal justice system. To pursue this goal, the organizers have solicited participants from a range of perspectives on these issues: researchers investigating the genetics and neurobiology of criminal, violent, and impulsive acts, and of related behavioral and psychiatric disorders; long-standing scientific critics of research on genetic factors of criminal behavior. historians, sociologists, and philosophers who will put the scientific research into historical, cultural, and intellectual perspective; criminal justice specialists who will gauge the impact of this research on criminal investigation and adjudication; and legal scholars and moral philosophers who will discuss how the discovery of genetic predispositions may affect our practice of punishment and our conception of moral responsibility. The study section was impressed with the diversity of views represented among the scholars and scientists who had agreed to participate in this working meeting.

I have attached a copy of the application, its pink sheet, and the conference brochure, for your use.

  
Eric T. Juengst, Ph.D.



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

National Institutes of Health  
Bethesda, Maryland 20892

June 23, 1992

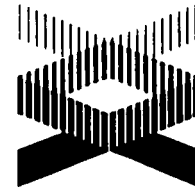
David;

Welcome back! Your conference brochure has gotten a lot of attention in your absence, as the attached suggests. It might be useful to spread the word that your understated statement of the issues was not intended to reflect an endorsement of genetic solutions to social problems!

Welcome to ELSI!

Eric

# Human Genome Project *Progress*



*from the National Center for Human Genome Research, National Institutes of Health*

June 18, 1992

TO: Don Ralbovsky

FROM: Leslie Fink

RE: Conference on Genetic Factors in Crime

Attached is the brochure on the meeting you asked about. As I said, it is not intended in any way to demonstrate unequivocal links between crime and genetics. Rather it is an opportunity for open discussion on all sides of the issue to help people understand the potential risks of thinking in terms of direct links and what impact that might have on policymaking. The roster of speakers includes opinions from all sides of the issue.

The program is being funded through a grant from our Ethical, Legal, and Social Implications Branch to David Wasserman at the University of Maryland's Institute for Philosophy and Public Policy. The director of the IPPP has been contacted by David Wheeler from the Chronicle of Higher Education about the conference and explained to him the broad nature of the conference agenda.

Interest in this conference has been triggered by a Dr. Peter Breggin, a Bethesda psychotherapist who has been a vocal critic of traditional psychiatry. Dr. Breggin appeared on a radio talk show (FM 102) yesterday morning apparently being critical of behavior research, the NIMH and Fred Goodwin, and was denouncing the ELSI conference. I was told all this by Elaine Baldwin at NIMH, 443-4536.

This is basically all I know at the moment. I'll be in touch if more develops.

*Leslie*

*cc: Michael  
Elle  
Mark  
Eric*





McGill

Department of Epidemiology  
and Biostatistics  
McGill University

1020 Pine Avenue West  
Montreal, PQ, Canada H3A 1A2

Fax: (514) 398-4503

4 June 1992

Eric T. Juengst, PhD  
Ethical, Legal and Social  
Implications Program  
National Center for Human Genome  
Research  
National Institutes of Health  
Building 38A, Room 610  
Bethesda, MD  
20892

Dear Eric:

We have just seen a copy of the brochure announcing a conference on "Genetic Factors in Crime: Findings, Uses & Implications" that the ELSI program appears to be co-sponsoring with The Institute for Philosophy and Public Policy (IPPP) at the University of Maryland in October. This brochure and the conference are both extremely troubling to us.

The introductory material in the brochure the IPPP is distributing appears to support a conservative political agenda that presents genetic research as a solution to social problems and inappropriately reifies the potential of genetic information. No matter how these issues are discussed when participants meet in the fall, interested people will be able to quote this authoritative source as acknowledging, for example, the "apparent failure of environment approaches to crime," the "early successes of research in the genetics of behavioral and psychiatric conditions" and the "prospect of identifying individuals who may be predisposed to...criminal conduct." In the current political climate, the probability that these claims will be used out of context but with accurate citation makes this brochure especially dangerous.

In addition, we are concerned about what can be illuminated or produced by this type of conference which seems to allow only for formal presentations. Already, 46 speakers are listed for the 3 day event. How can this possibly allow for the extended time required for all participants to examine in context and with all their nuances the many issues on the agenda? Why have the topics scheduled been selected and why are they being addressed in this cursory fashion?



McGill

Eric T. Juengst, PhD, 4 June 1992, Page 2

There are critical questions of substance to be investigated with support from the ELSI program and responsible ways to investigate them. We are concerned about the potential of this conference to contribute to these investigations and alarmed by the irresponsible way in which this particular investigation seems to be constructed.

Sincerely yours,

*Abby Lippman*

---

Abby Lippman  
Chair, Human Genetics Committee  
Council for Responsible Genetics

*Nachama Wilker*

---

Nachama Wilker  
Executive Director  
Council for Responsible Genetics

Eric/Elinor: FYI

RECORD OF CONGRESSIONAL INQUIRY RECEIVED BY TELEPHONE

INQUIRY FROM OFFICE OF SENATOR <input checked="" type="checkbox"/> REP Conyers	STATE MI	TIME 3:00	DATE 6/2/92
NAME OF CALLER Sherille Ismail	CALL RECEIVED BY Cheryl McMillen	ORGANIZATION (BID, etc.) NEHGR	
INFORMATION REQUESTED AND ACTION TAKEN			

Information requested on the Ethical, Legal, and Social Implications program and its "position" regarding research on genetic factors involved in criminal behavior.

Sent (faxed) a copy of a brochure announcing a conference on the above topic. The conference is sponsored by Elsi and the brochure is attached.

DATE AND TIME RESPONSE PROVIDED (if applicable) 6/4/92 3:00	RESPONSE PROVIDED BY (if applicable) Cheryl McMillen
--	---

**NATIONAL CENTER FOR  
HUMAN GENOME RESEARCH, NIH**



**FAX TRANSMITTAL SHEET**

TO: *Mr. Sherille Ismail*

FAX NUMBER: *225-4784*

FROM: Cheryl McMillen

DATE: *6/4/92*

# of pages including cover sheet: *4*

Return FAX number: [REDACTED]

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Comments:

*I hope this is useful to you. I will forward other information as it is available. If I can be of further help, please call*

*Cheryl McMillen*

# GENETIC FACTORS IN CRIME: FINDINGS, USES & IMPLICATIONS



October 9-11, 1992

A conference sponsored by  
The Institute for Philosophy and Public Policy  
and The National Institutes of Health



Researchers have already begun to study the genetic regulation of violent and impulsive behavior and to search for genetic markers associated with criminal conduct. Their work is motivated in part by the early successes of research on the genetics of behavioral and psychiatric conditions like alcoholism and schizophrenia. But genetic research also gains impetus from the apparent failure of environmental approaches to crime -- deterrence, diversion, and rehabilitation -- to affect the dramatic increases in crime, especially violent crime, that this country has experienced over the past 30 years. Genetic research holds out the prospect of identifying individuals who may be predisposed to certain kinds of criminal conduct, of isolating environmental features which trigger those predispositions, and of treating some predispositions with drugs and unintrusive therapies.

The Institute for Philosophy and Public Policy is sponsoring a conference to consider the implications of this research. We are bringing together researchers investigating the heritability and neurobiology of criminal conduct and of related behavioral and psychiatric disorders; historians, sociologists and philosophers who will put this research into cultural and intellectual context; criminal justice experts who will gauge the impact of this research on investigation and adjudication; legal scholars and ethicists who will discuss its impact on sentencing practices and conceptions of moral responsibility. This conference will integrate the concerns and findings of several disciplines on a range of topics, from the mathematical modeling of polygenic disorders to the courtroom use of genetic-predisposition evidence.

The goal of the conference will not be to achieve consensus: it would be naive to expect agreement among scholars and practitioners committed to different assumptions, methodologies and values.

Rather, our goal will be to clarify and narrow their areas of disagreement: about the present state of research, e.g., whether specific findings are replicable; about the interpretation of that research e.g., whether accepted findings are generalizable to other populations or other criminal offenses; and, finally, about moral and policy issues raised by the research, e.g., how does the capacity to predict and explain misconduct affect the appropriateness of blame and punishment? In sum, we hope to improve the ratio of light to heat in a debate that will only intensify as findings about the heritability and neurobiology of violent and antisocial behavior proliferate, and as proponents of genetic explanation become more ambitious.

## TENTATIVE CONFERENCE SCHEDULE

### Day 1, Morning Session(s)

- I. The biological & genetic explanation of crime in the context of late 19th and early 20th century natural and social science.
- II. The revival of biological and genetic explanations of crime and social behavior.

### Day 1, Afternoon Session(s)

- I. Current genetic research on multifactorial disorders: strategies and findings.
- II. Genetic research on alcoholism and psychiatric disorders: alcoholism, schizophrenia, bipolar disorders.

### Day 1, Evening Roundtable

The XYY controversy as precedent

### Day 2, Morning Session(s)

- I. Statistical & demographic studies on the heritability of crime and anti-social behavior.
- II. The neurology and psychopharmacology of impulsive, violent & aggressive behavior.

### Day 2, Afternoon Session(s)

- I. The social construction of crime and the possibility of bio-genetic explanation.
- II. Genetic and environmental interaction: how and what can genetics explain?

### Day 3, Morning Session(s)

- I. What can we learn from the integration of recent scientific and technological developments by the criminal justice system?
- II. The role of genetic-predisposition information in criminal investigation and adjudication.

### Day 3, Luncheon Roundtable

The introduction of forensic DNA typing.

### Day 3, Afternoon Session(s)

- I. Genetic predisposition and criminal responsibility: legal and moral issues.
- II. Intervention and treatment: can drug therapy ever be benign? To whom should it be offered, on whom should it be imposed?

## CONFERENCE ARRANGEMENTS

Fee: A \$30.00 registration fee per person is required with the Advance Registration Form. Please make your checks payable to the University of Maryland Foundation. Advanced registration is advised; seating is limited to 150. The registration fee is refundable if registration is canceled prior to September 18, 1992.

Accommodations: The conference will be held at the Center for Adult Education on the campus of the University of Maryland in College Park. Hotel rooms are available at the following hotels: Quality Inn (301) 864-5820, \$44.00 per night for a single room and \$49 per night for a double room; the Holiday Inn (301) 345-6700, \$68 per night flat rate single or double; the Best Western Maryland Inn (301) 474-2600, \$55.00 per night flat rate single or double; the Comfort Inn (800) 395-4678, \$40.00 per night flat rate single or double (all room rates are plus tax). A limited number of rooms have been reserved at these rates. Please mention the "Genetic Factors" conference when making your reservations. These rooms will be filled on a first come-first served basis. To ensure a room please make your reservation by September 18, 1992.

Meals: Three luncheons at a charge of \$13.00 per luncheon and one dinner at a charge of \$25.00 are scheduled. Reservations for these meals must be made in advance and payment should be enclosed with the Advance Registration Form. Cafeteria service meals and luncheon dining room service are available in the Adult Education Center to conference participants on an individual cash basis.

### LIST OF SPEAKERS AS OF MARCH 20, 1992:

- Garland E. Allen**, Department of Biology, Washington University.
- Jonathan R. Beckwith**, Department of Microbiology-Genetics, Harvard Medical School.
- Paul R. Billings**, Human Genome Center, Laurence-Berkeley Laboratory.
- Robert Bonn**, Department of Sociology, John Jay College of Criminal Justice.
- JoAnn Boughmann**, Human Genetics Division, University of Maryland, Baltimore.
- Patricia Brennan**, Department of Psychology, University of Southern California.
- Gerald L. Brown**, National Institute on Alcohol Abuse & Alcoholism.
- Gregory Carey**, Institute for Behavioral Genetics, University of Colorado.
- Gary Chase**, Dept. of Mental Hygiene, Johns Hopkins University.
- Maimon Cohen**, Director, Human Genetics Division, University of Maryland, Baltimore.
- Gerald Cooke**, Neuropsychologist, Phil., PA.
- Elliot Currie**, Institute for the Study of Social Change, Berkeley, CA.
- Stephen Dinwiddie**, Department of Psychiatry, Washington University School of Medicine.
- Troy Duster**, Department of Sociology, University of California-Berkeley.
- John M. Fischer**, Department of Philosophy, University of California, Riverside.
- Diana Fishbein**, Criminal Justice Department, University of Baltimore.
- Ellot Gershon**, National Institute of Mental Health.
- Frederick H. Gifford**, Department of Philosophy, Michigan State University.
- Steven Goldberg**, Georgetown Univ. Law Center.
- David Goldman**, National Institute on Alcohol Abuse & Alcoholism.
- Irving Gottesman**, Department of Psychology, University of Virginia.
- Patricia Greenspan**, Department of Philosophy, University of Maryland.
- Samuel B. Guze**, Department of Psychiatry, Washington University School of Medicine.
- Peter Hoffman**, Principal Technical Advisor, U. S. Sentencing Commission.
- Eric Lander**, Whithead Institute of Biology.
- Richard Laymon**, National Institute of Justice.
- Richard Lempert**, Univ. of Michigan Law School.
- Markku Linnolla**, National Institute on Alcohol Abuse & Alcoholism.
- Sarnoff Mednick**, Department of Psychology, University of Southern California.
- Terrie E. Moffitt**, Department of Psychology, University of Wisconsin.
- Norval Morris**, University of Chicago Law School.
- Dorothy Nelkin**, Dept. of Sociology, New York University.
- Ernest P. Noble**, UCLA Medical School, Department of Psychiatry.
- Diane Paul**, Department of Political Science, University of Massachusetts.
- Joseph Peterson**, Department of Criminal Justice, University of Illinois at Chicago.
- Phillip Reilly**, Director, Shriver Institute.
- Robert Ressler**, FBI Behavioral Science Investigation and Research Unit (retired).
- Arthur Robinson**, National Jewish Center Hospital.
- David Rowe**, Division of Family Studies, University of Arizona.
- Robert Sadoff**, Neuropsychiatrist, Phil. PA.
- Michael Slote**, Department of Philosophy, University of Maryland.
- William C. Thompson**, Program in Social Ecology, University of California-Irvine.
- Michael Tonry**, Univer. of Minnesota Law School.
- Richard Wetzell**, History Dept., Univ. of Maryland.
- James Wilson**, Graduate School of Mgmt., UCLA.
- Franklin E. Zimring**, University of California School of Law.

# ADVANCE REGISTRATION FORM

Name \_\_\_\_\_

Affiliation \_\_\_\_\_

Address \_\_\_\_\_

A \$30.00 fee payable to the University of Maryland is required to reserve a place at the conference. This deposit is refundable if registration is cancelled prior to September 18.

Mail to:  
Carroll Linkins, Conference Coordinator  
Institute for Philosophy and Public Policy  
University of Maryland  
College Park, MD 20742  
(301) 405-4753

Please check registration requirements:

I plan to attend:

_____ "Genetic Factors" Conference, October 9-11	\$30.00
_____ Luncheons @ \$13.00 (circle desired luncheons) Friday, Saturday, Sunday	\$ _____
_____ Dinner (Friday evening)	\$25.00
_____ Total Enclosed	_____



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

National Institutes of Health  
Bethesda, Maryland 20892

1R13 HG00703-01

May 11, 1992

David T. Wasserman, J.D.  
Research Scholar  
Institute for Philosophy  
& Public Policy  
University of Maryland  
Room 0123 Woods Hall  
College Park, MD 20742

Dear Dr. Wasserman:

I am returning your letter and budget pages requesting a supplement of \$7,000 to the amount requested in your original budget. As I explained to you over the phone, any request submitted must have your signature and that of the official signing for your organization.

Once we receive your request with the appropriate signatures we will be happy to give it our prompt attention.

If you have any questions concerning this matter, please contact Linda Hall at [REDACTED].

Sincerely yours,

*Linda M. Hall*  
Linda M. Hall  
Grants Management Specialist  
National Center for Human  
Genome Research

*Eric Juengst*  
Eric Juengst Ph.D.  
Director, ELSI Program  
National Center for Human  
Genome Research

PREPARED BY: LINDA HALL 5/11/92

BCC: DR. JUENGST, OFFICIAL FILE, BOARD FILE, GMS



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Mar 16 4 12 PM '92

UNIVERSITY OF MARYLAND AT COLLEGE PARK

INSTITUTE FOR PHILOSOPHY AND PUBLIC POLICY

March 11, 1992

Eric Juengst, Director  
Ethical, Legal and Social Implications Program  
National Center for Human Genome Research  
National Institutes of Health  
Bethesda, MD 20892

Re: Genetic Factors in Crime:  
Findings, Uses, Implications

Dear Eric:

I am writing to request a supplement of \$7,000 to the amount requested in the original budget. This amount would be used to cover cost overruns in running the conference; it would not go towards the anthology. The three sources of additional expenses are the larger number of participants I now expect, the rental of the University Conference Center auditorium, and the videotaping. I enclose a copy of the budget and budget-justification from the original proposal, and a copy of the contract we plan to sign with the University Conference Center.

1) Because of invitations suggested by the study section and a high response rate, I may have as many as 12 more participants than I budgeted for: roughly 6 local, and 6 from out of town. This means that our total airfare may go up by  $\$650 \times 6 = 3,900$ , along with  $\$80 \times 6 = 480$  for airport ground transportation (the budget estimates of air and ground fare still seem realistic). Throwing in another \$120 for car mileage for local (DC and Balt.) participants, this leaves a possible overrun of \$4,500.

We have reserved 40 hotel rooms, rather than 30, but since we receive a 15% discount on rates that are somewhat lower than anticipated, I do not expect additional lodging expenses. The discount does not apply to food, however; food costs may go up by 12 participants  $\times$  \$50/day  $\times$  3 days, or \$1,800. (the \$50 figure builds in a slight increase over current prices, since the food service arrangements will not be made until shortly before the

conference. At present rates, lunches run over \$10 per person; dinners, almost \$20; then there's breakfast and two daily snack breaks.)

Thus, the extra participants may cost us as much as \$6,300.

2) We budgeted \$450 for meeting rooms. The rental turns out to be \$1,785, less a 15% discount. This allows us exclusive use of the Conference Center's superb 500+ seat auditorium (250 seats with retractable desks) for two days. (the auditorium was already booked for the third day, so we will be using another room, very adequate but smaller.) This is about \$1000 above our estimate.

3) We budgeted \$1,000 for videotaping; the study section recommended \$10,000. As I indicated to you, I don't think we will need anything like the latter amount, since we should be able to get state-of-the art equipment and assistance from the the U of M Department of Radio, Television, and Film. But even with in-house support, the cost of producing high-quality videotapes of a full three-day conference may be alot more than we anticipated. \$3000 seems like a prudent estimate.

Thus, our total expected overrun is \$6,300 (additional participants) + 1,000 (meeting-room rental) + 2,000 (video-taping) = \$9,300.

We are planning to charge a \$50 registration fee, but we would like to apply half of this to lunch and dinner, to keep the conference available to those without grants or expense accounts. While we hope to get 200 people, we can't count on more than 100 (another 50 spaces will be reserved for U of M students, faculty, and other invited guests). This will give us \$2,500 to defray the overruns. Rounding off, the difference is \$7,000, which I hope you will be able to cover. It will not only enable the conference organizers to sleep easier, but give us flexibility to improvise, if, as we expect, things don't go quite as expected.

Thanks for your assistance,

Automatic Withdrawal Date:  
March 31, 1993

January 27, 1992 Council  
Our Reference: 1R13HG00703-01 EJS503

Dr. David T Wasserman  
University of Maryland  
College Park, Md 20742

Dear Dr. Wasserman:

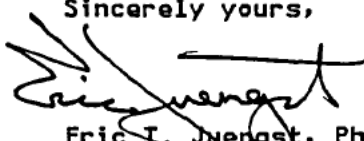
The initial peer review of your grant application referenced above has been completed. The evaluation of your application by the initial review group is summarized in the enclosed Summary Statement. As you are aware, the NIH adopted a new scoring system September 1, 1991. An information sheet explaining the new scoring system is enclosed.

The next step in the peer review process will be the consideration of your application by the National Advisory Council for Human Genome Research at its meeting in January. You will be notified of the outcome soon after the Council meeting.

A new feature of the Summary Statement is that it now shows the "ESTIMATED TOTAL COSTS" as part of the budget recommendation. The estimated total cost does not enter into the scientific evaluation of applications. The calculation of the estimated total cost is explained in the September 6 issue of the NIH Guide to Grants and Contracts. This information is provided to the National Advisory Council for Human Genome Research as part of the NIH Cost Management Plan. A copy of this plan is available from the NCHGR upon request.

If you have any questions about the action taken on your application or the opinions expressed in the Summary Statement at this stage of the review process, please contact me immediately. I would appreciate receiving any correspondence relating to the Summary Statement as soon as possible.

Sincerely yours,



Eric T. Juengst, Ph.D  
Program Director,  
Ethical, Legal, and Social  
Implications Program  
National Center for Human Genome Research  
[REDACTED]

Enclosures

bcc: HG file, PA board

JAN 28 1992

Automatic Withdrawal Date:  
March 31, 1993

January 27, 1992 Council  
Our Reference: 1R13HG00703-01 EJS503

Dr. David T Wasserman  
University of Maryland  
College Park, Md 20742

Dear Dr. Wasserman:

The National Advisory Council for Human Genome Research considered your application, identified above, at its most recent meeting. The Council concurred with the recommendation of the initial review group as described in the summary statement previously sent to you.

As yet, we have not made any funding decisions on applications reviewed at this recent Council meeting. I will contact you should the NCHGR be able to fund your application. Please note that the Notice of Grant Award is the only official notification that a grant has been awarded. Therefore, you should not incur any financial obligations or commitments based on this letter. In the event you are informed verbally of our intent to fund your application and you or your institution plan to announce this information publicly, I would encourage you to coordinate the release of this information with NCHGR staff.

If your application is not paid in the near future, it will remain in competition for funding until the automatic withdrawal date noted above. Should you receive funding for any part or all of this project from another source before that date, or if there are any other changes in your status, it is important that you inform me immediately.

Sincerely yours,



Eric T. Juangst, Ph.D  
Program Director,  
Ethical, Legal, and Social  
Implications Program  
National Center for Human Genome Research  
[REDACTED]

cc: Business Official

bcc: HG file, PA board