

Withdrawal/Redaction Sheet

Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001a. fax	To: Chris Jennings re: Draft Executive Order (partial) (1 page)	01/14/2000	P3/b(3)
001b. letter	To: Chris Jennings re: Draft Executive Order (partial) (1 page)	01/14/2000	P3/b(3)
002. memo	Murray Katz to Chris Jennings re: A Solution to the Rising Price of Pharmaceuticals (partial) (1 page)	06/20/2000	P6/b(6)
003. note	re: phone number (1 page)	n.d.	P6/b(6)
004. letter	To: Mac Reed re: Exectuive Order (partial) (1 page)	03/02/1999	P3/b(3)
005. letter	To: Mac Reed re: Exectuive Order (partial) (1 page)	03/11/1999	P3/b(3)
006. list	re: contact information (partial) (1 page)	03/10/1999	P3/b(3)

COLLECTION:

Clinton Presidential Records
Domestic Policy Council
Devorah Adler
OA/Box Number: 20146

FOLDER TITLE:

Genetic Discrimination [Folder 3]

2012-0463-S

rc757

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

- P1 National Security Classified Information [(a)(1) of the PRA]
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C. Closed in accordance with restrictions contained in donor's deed of gift.

PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).

RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

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OFFICE OF THE CHAIRWOMAN

U.S. Equal Employment Opportunity Commission
1801 L Street, N.W.
Washington, D.C. 20507
(202) 663-4001
(202) 663-4110

FACSIMILE COMMUNICATION

DATE: January 14, 2000

TO: Chris Jennings

ORGANIZATION: Executive Office of the President

FAX NO.: (202) 456-5557

SENDER: Louis Lopez

TELEPHONE NO.: (202) 663-4098

**NO. OF PAGES
(INCLUDING COVER):** 2

MESSAGE: Please see attached. Thanks.



U.S. EQUAL EMPLOYMENT OPPORTUNITY COMMISSION
Washington, D.C. 20507

Office of the
Chairwoman

January 14, 2000

Mr. Christopher W. Jennings
Deputy Assistant to the President for Health Policy
216 Old Executive Office Building
Washington, D.C. 20502

Re: Genetic Discrimination Executive Order

Dear Chris:

We have reviewed the January 11, 2000 draft of the referenced Executive Order as well as the comments that are being submitted by the Department of Labor (DOL). As the DOL submission states, the U.S. Equal Employment Opportunity Commission (EEOC) concurs with the comments set forth therein.

We write separately to address the language in section 1-103 of the draft Executive Order. Specifically, section 1-103 states that "[t]he Equal Employment Opportunity Commission shall be responsible for coordinating the policy of the Government of the United States to prohibit discrimination against employees in Federal employment based on protected genetic information or information about a request for or the receipt of genetic services." The draft Executive Order further states in section 1-403 that it "does not create any right or benefit, substantive or procedural, enforceable at law by a party against the United States, its officers or employees, or any other person."

Based on these sections and earlier discussions at the meetings in your office, it is our understanding that the draft Executive Order contemplates that the EEOC will prepare guidelines or a policy statement concerning genetic discrimination in federal employment. We would prepare the guidelines with input from the same stakeholders who have participated in the drafting of the Executive Order. These guidelines would note, among other things, that although the Executive Order does not create any substantive or procedural right or benefits, federal employees and applicants may raise concerns regarding the use of genetic information within the context of the Rehabilitation Act, which the EEOC does enforce. Please let me know whether our understanding of the EEOC's role following execution of the Executive Order comports with yours.

Thank you for the opportunity to participate in the drafting of the Executive Order. If you have any questions concerning the foregoing, please do not hesitate to call me at (202) 663-4098.

Sincerely,

A handwritten signature in cursive script, reading "Louis Lopez", is written over the typed name.

Louis Lopez

Attorney-Advisor to the Chairwoman

Edward A. Frankle, Esq.
General Counsel
NASA
Washington, DC 20546
(202) 358-2450

facsimile transmittal

To: Christopher Jennings, Deputy
Assistant to the President for Health
Policy

Fax: 202-456-5557

From: Edward A. Frankle

Date: 1/14/00

Re: Genetic Discrimination Executive
Order

Pages: Cover plus 1

CC:

☒ Urgent

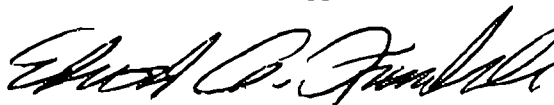
☐ For Review

☐ Please Comment

☐ Please Reply

☐ Please Recycle

Notes: Per your request, NASA has reviewed the draft Executive order. The changes made in the most recent version address most of NASA's concerns. As explained in the enclosed memorandum from our medical staff to me, the current version presents no problem regarding the vast majority of our employees and has only small, but acceptable impacts on the astronaut corps as it currently exists. We do feel that when the time comes to begin selecting crews to go on long duration missions, such as to Mars or the moon, other problems may well arise. Those issues are, at least, several years in the future and are best addressed when they arise in a full factual context. Therefore, recognizing that policy on this important topic will and must evolve as we learn more about the use of genetic information, NASA has no objection to the issuance of the version of the Executive order distributed for comment on January 12, 2000. Thank you for the opportunity to comment and participate in this review.



~~CONFIDENTIAL~~

DETERMINED TO BE AN
ADMINISTRATIVE MARKING
INITIALS: ELF DATE: 08/11/12
2012-0463-S

National Aeronautics and
Space Administration
Headquarters
Washington, DC 20546-0001



JAN 14 2000

Reply to Attn of:

UH

TO: G/General Counsel

FROM: UH/Director, Office of Health Affairs

SUBJECT: Proposed Executive Order to Prohibit Discrimination in Federal
Employment Based on Predictive Genetic Information

1. We have reviewed the revised draft of the proposed Executive Order. We believe that compliance with this order will not negatively impact our operations for our ground-based workforce, for those workers engaged in underwater activities, and for those individuals engaged in atmospheric flight operations.
2. With respect to operations in space, there is potential liability. Space is the most extreme and unforgiving environment into which humans have ever ventured. In space, small crews of people are utterly dependent on each another for survival, and failure of one for any reason may mean disaster for all. We have depended on strict selection standards to minimize the risk of medical problems during space missions and have been well served by this practice. For short duration missions, the proposed Executive Order will probably not negatively impact operations. During long duration missions, however, genetic traits that were latent at launch may manifest as disease, endangering not only the individual but also the entire crew. Inability to use predictive genetic information for flight assignment in this context may therefore represent a prohibitive risk.
3. We believe that an exception to this proposed Order applicable to the Astronaut Corps may ultimately be necessary to protect the health and safety of long duration space crews. We can, however, comply with the proposed order without untoward effect at present, for short duration space flight missions.

A handwritten signature in black ink, appearing to read "Richard S. Williams".

Richard S. Williams, MD

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001a. fax	To: Chris Jennings re: Draft Executive Order (partial) (1 page)	01/14/2000	P3/b(3)

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RR. Document will be reviewed upon request.

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FAX TRANSMITTAL / MESSAGE SHEET

TO:	(Organization, Name, Office Telephone, as needed)	
	Mr. Christopher C. Jennings Deputy Assistant to the President for Health Policy	
RECEIVING FAX NUMBER:		202/456-5557
DATE TRANSMITTED:		14 January 2000
ORIGINATING FAX NUMBER		P3/(b)(3)
ORIGINATOR:		P3/(b)(3) Associate General Counsel, CIA
SUBJECT: Draft Executive Order "To Prohibit Discrimination in Federal Employment Based on Predictive Genetic Information"		
NUMBER OF PAGES (Including This		2
MESSAGE / REMARKS		

[001a]

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001b. letter	To: Chris Jennings re: Draft Executive Order (partial) (1 page)	01/14/2000	P3/b(3)

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CENTRAL INTELLIGENCE AGENCY

WASHINGTON, D.C. 20505

Office of General Counsel

14 January 2000

Mr. Christopher C. Jennings
Deputy Assistant to the President
for Health Policy
216 Old Executive Office Building
Washington, DC 20502

Dear Mr. Jennings:

This is to convey this Agency's concurrence with the language in the 11 January 2000, 5:00 p.m. draft Executive Order "To Prohibit Discrimination in Federal Employment Based on Predictive Genetic Information." We still have serious concerns regarding the breadth of the definition of "protected genetic information" in section 1-201(e) of the draft, particularly in light of the fact that it has not been the subject of public debate. Nevertheless, because the exceptions provisions of section 1-301 respond to our equities, we can concur with this draft overall.

If we can provide any additional information or you have questions regarding CIA's equities or this response, please feel free to call me or [REDACTED] P3(b)(3) You can reach me at [REDACTED] P3(b)(3) number is [REDACTED] P3(b)(3)

Sincerely,

[REDACTED] P3(b)(3)

[0016]

Representative **Louise Slaughter**

News Release

28th District • New York

PHONE (202) 225-3615 • FAX (202) 225-7822

E-MAIL: louiseny@mail.house.gov • WEB ADDRESS: <http://www.house.gov/slaughter/>



For Immediate Release
June 19, 2000

Contact: Becky Bailey
202-225-3615

DEMOCRATS PUSH FOR FLOOR VOTE TO BAR GENETIC DISCRIMINATION

WASHINGTON—An announcement is expected next week that scientists have mapped the human genome. While the benefits are promising, Americans who undergo genetic testing risk losing their health insurance and/or employment if test results reveal faulty genes, even though there may be no symptoms. Congresswoman Louise M. Slaughter has spent five years pushing for legislation to bar insurance companies and employers from discriminating on the basis of genetic information. The Majority has refused to even hold a hearing on Slaughter's legislation.

On Wednesday, June 21, House Minority Leader Richard Gephardt and Rep. Slaughter will lead Democrats from the Caucus meeting room (345 Cannon) to the House chamber to sign a discharge petition for a floor vote on Slaughter's bill, The Genetic Nondiscrimination in Health Insurance and Employment Act (H.R. 2457). If the petition gathers 218 signatures, the House would be forced to vote on the bill.

Following the procession to the Chamber there will be a news conference at the House Triangle, in which Senate Minority Leader Daschle and Senator Kennedy are expected to participate. They are sponsoring the companion bill in the Senate, S. 1322.

DETAILS OF EVENT FOLLOW:

WHO:

- (1) Minority Leader Richard Gephardt, Democratic Leadership, Rep. Louise Slaughter and House Democrats to walk en masse to chamber.
- (2) Senators, genetic discrimination victim and health advocacy groups will join Slaughter, Gephardt and House Democratic leaders at news conference.

WHAT:

Democrats to walk from caucus room (Cannon 345) to House chamber to sign discharge petition barring genetic discrimination; news conference to follow at House Triangle

WHEN & WHERE:

Wednesday, June 21: Walk to House chamber 9:30 a.m.-10:00 a.m.; News conference at House Triangle at 10:30 a.m.; Rain site: 122 Cannon

urgent

f a c s i m i l e

To: **Mr. Chris Jennings, Health Policy Coordinator**

Company:

Fax Number: +1 8,2024565557

Business Phone:

From: **Murray A. Katz, M.D.**

Fax Number: +1 (520) 629-1801

Business Phone:

Home Phone:

Pages: 5

Date/Time: 06/20/2000 10:12:12 AM

Subject: An alternative to the Thomas Bill and price controls for drug costs.

From: Murray A. Katz, M.D.
Staff Nephrologist and Chief
Professor of Internal Medicine and Physiology
University of Arizona College of Medicine
Director, Benjamin W. Zweifach Microcirculation
Laboratories
Research Service (0-151)
Tucson Department of Veterans Affairs Medical Center
Tucson, Arizona 85723

Phone: 520-629-4763
Fax: 520-629-1801
e-mail: mkatz@theriver.com

Date: June 20, 2000

Subject: A solution to the rising price of pharmaceuticals
without new laws nor price controls, specifically without
the Thomas Bill

To: Chris Jennings
White House Health Policy Coordinator

Dear Mr. Jennings:

Most of the current solutions being discussed on how to fix the high price of pharmaceuticals revolve about hammering the drug companies or establishing price controls. Both of these are counterproductive. Moreover, you are correct in assessing the Thomas Bill as a recipe for wheedling the HMOs, and we've been down that road before blowing 100,000 to entice employers to insure their employees. Now, fewer than half do. I would appreciate your consideration of a different option.

In January, 2000, I was asked, as a student of the MCO movement in the world, by the largest MCO in the state of Arizona to develop a test plan to reduce the cost of antihypertensive drugs for the population and compute the expected benefit to cost ratio for the company. I presented the plan in March, which won quick approval by the Chief Medical Officer and his staff. I was asked to make some modifications and present this to the CEO for action. The changes were made, and in April, the CEO, not a clinician, felt that the investment was too large to be made at this time. I should like to present the elements to you, so that you might get an idea how government can be a participant in furthering excellence in the practice of medicine and to do so with minimal drug costs.

The program has four parts: 1) Education of members and primary care providers on the benefits of generic medications above trade name medications. 2) Tracking of primary care providers for their practice patterns for a reward system only. 3) Multimedia campaign to educate providers and patients on the

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benefits of generics over brand names. 4) Recruitment of generic companies to participate in the cost with the expectation that they will profit from a larger market share.

The analysis of this plan in a selected market in Pima County in southern Arizona yielded the following estimates of a 12 month fiscal activity:

The total cost of the program distributed over an MCO population of 191,685 members is \$609,600 for \$3.18 per member. Public media reaches 375,000 members of all MCOs in Pima county. Assuming no new members, the maximum profit for the company in Pima county is \$10,530,000 and for all MCOs in the area, \$37,940,000 representing a 17.3 fold profit/investment over a year. This would mean a net profit of \$9.92 M or \$95/member/year with a treatment regimen which is equal to if not better than the name brand therapy.

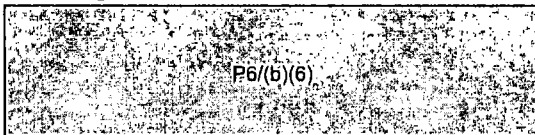
Senator Orrin Hatch and Congressman Henry Waxman got recognition of generic companies in 1985, and they are poised and ready to fill the gap with drugs which are chemically identical to and biologically equally available as the name brands. They will share in the costs of such a program if they see benefits for them in market share. The large pharmaceutical companies are not in any great trouble from this plan. They are 10 to 15 billion market cap companies, while the 27 generic companies supplying antihypertensives vary from 75 to 300 million market cap.

From hypertension, one can easily move into antibiotics, antipsychotics, and others.

I should be happy to present the entire plan and structure to you or your staff. From a subtle governmental push, HMOs would be carried along with pressure to establish such programs with the saving of most of the inflationary pressure on drug costs. This requires no price fixing, which spirals out of control as soon as the controls are lifted-as we learned after the Nixon price controls on medical care were lifted.

Sincerely yours,

Murray A. Katz, M.D.



[002]

* * * * *

Brief Profile of Murray A. Katz, M.D.

Murray A. Katz, M.D.
Staff Nephrologist and PCP, Department of Veterans Affairs

Professor of Internal Medicine and Physiology
Director, B. W. Zweifach Microcirculation Labs.
Research Service (0-151)
Department of Veterans Affairs Medical Center
3601 South 6th Avenue
Tucson, Arizona 85723

Phone: 520-629-1824
Voice Messaging: 520-629-4763
FAX: 520-629-1801
email: mkatz@theriver.com

Brief Resume of Murray A. Katz, M.D.

PROFILE: Extensive knowledge and experience as physician, educator and researcher. Board certified internist, nephrologist. Active practice in varied patient settings: government HMO system, contract military patients and dependants, university patients, both inside and outside hospital. Active consulting physician for difficult-to-manage patients with high blood pressure/diabetes/kidney disease, as well as teacher/consultant for colleagues and new providers. Former HMO manager as well as deliverer of care. As educator, teach a broad range of subjects to a varied groups of students: the art and science of medicine, nephrology, physiology, biochemistry, statistics, basic and outcomes research methods, and mathematical modeling. As a researcher, published over 58 first author papers, books, and book chapters in a wide range of subjects ranging from diabetes, kidney disease, physiology, and biomathematics. Lectures frequently on the outcomes of medical practices and the most likely shape of future practice. Research has been invited for presentation regionally, nationally, and internationally. Associate editor and reviewer for many journals.

HIGHLIGHTS OF QUALIFICATIONS

- * Statistics and Higher Mathematics
- * Medical Research
- * Statistical & Model Program Development
- * Clinical Investigation cost free to VA
- * Hospital Performance Measures
- * Microcirculatory Research & Practice
- * President's Council on Improving Calculus Instruction
- * Nephrology, Internal Medicine
- * University Instruction

SELECTED ACHIEVEMENTS

- * Teaching health professionals enthusiasm for career. Success

has been met by looking ahead to medical practice decades away. Trainees and Nurse Primary Care Providers are taught that a "fever and a cough" requires only a single five minute evaluation; not two visits, a chest X-ray, and a CBC. "Healthy" clients are trained to teach other clients "healthy behaviors".

* Guided the Tucson Veterans Affairs Research Service through largest and most sustained growth and diversification during scarce federal research funding. This program was developed by one-on-one teaching of new researchers in the preparation and methods for success.

* Designed the mechanisms whereby all Tucson VA HMO patients can avail themselves of all locally approved research protocols (including cancer trials) at no cost to patients nor the VA.

PROFESSIONAL EXPERIENCE

Department of Veterans Affairs Medical Center, Tucson, AZ	1974-Present
Frontline Managed Care Primary Care and Renal Specialty Provider	1974-Present
Associate Chief of Staff for Research	1981-1997
Medical Executive Committee Member and HMO Planner	1992-1997
Founding Director of the Benjamin W. Zweifach Microcirculation Laboratories	1984-Present
Assistant to Full Professor of Internal Medicine (Youngest Full Professor)	1974-Present
Full Professor of Physiology	1984-Present
Teaching of skills to doctors, medical students, nurses, and K-12 students	1966-Present

EDUCATION

Renal Fellowship Training, University of Texas Southwest Medical School, Dallas, TX

Osler Medical House Staff Training, Johns Hopkins University School of Medicine, Baltimore, MD

M.D., B.A., Johns Hopkins University School of Medicine, Baltimore, MD (Minor in English with General and Departmental Honors)

LIZ ROBBINS ASSOCIATES

441 New Jersey Ave., SE
Washington, D.C. 20003
202/544-6093
Fax: 202/544-1465

Washington Representatives
E-Mail: robassoc@crols.com

2211 Broadway
New York, NY 10024
212/580-2308
Fax: 212/580-8048

FAX NUMBER: 202-456-5557

To: Chris Jennings

Date: June 20, 2000

From: Liz Robbins

Pages: 2

Chris-

This is the letter that twelve Governors including Pataki are about to send to the President, VP, and the Hill. Gov. Ryan is holding it for a few minutes in case there might be any new news, but since the other Governors have it there might be a leak. I understand that despite the fact there are five Democrats on the letter, the release might not be pretty.

5 Dem
7 Reps.

June 19, 2000

The Honorable William J. Clinton
President of the United States
Executive Office of the President
1600 Pennsylvania Avenue, N.W.
Washington, DC 20500

Dear President Clinton:

We are writing to express our strong opposition to a pending rule that will reduce Federal Medicaid for states. The U.S. Department of Health and Human Services has publicly announced its intention to publish regulations that would dramatically restrict the ability of states to use federal funds through the Medicaid program to provide health services for many of our nation's poorest, most vulnerable and underserved citizens. We ask that you reconsider this regulatory change and choose not to move forward with the alteration.

In 1991, Congress reaffirmed the states' ability to use local government funds for the purpose of obtaining increased federal Medicaid matching funds. The agreement to maintain this option occurred at the same time that Congress eliminated other sources of Medicaid matching funds that were previously available to the states.

Now almost ten years later, the Department of Health and Human Services is proposing to radically restrict this program without an adequate assessment of the impact that such a change would have on state health care budgets. More specifically, we believe there has not been sufficient consideration of any alternative approaches that might lessen the negative impact on the poor, elderly and medically needy.

Let us be clear: The states' ability to continue to provide vital health services to our poorest and most vulnerable citizens will be greatly impaired should this proposal be adopted by your Administration. Examples of programs that are likely to be curtailed include services in public hospitals and county nursing homes serving indigent populations, home and community based care for the elderly, programs that assist the disabled to live independently in the community, expansion of the Children's Health Insurance Program, efforts to reduce the number of uninsured and optional services for Medicaid recipients.

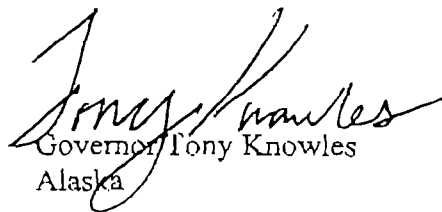
President Clinton
June 19, 2000
Page 2

Given the negative consequences of this proposal and the Department's expressed intent to move forward as quickly as possible -- without adequate analysis of the regulation and its unintended consequences -- we respectfully request that you not allow HHS to publish this regulation.

Sincerely,



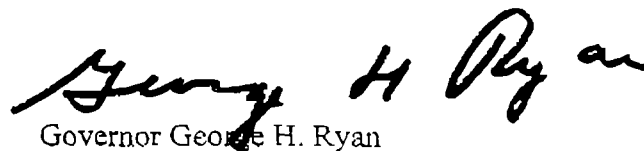
Governor Don Siegelman
Alabama



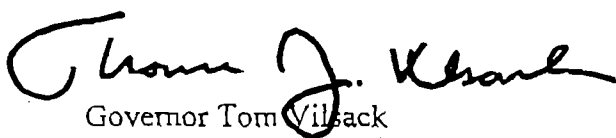
Governor Tony Knowles
Alaska



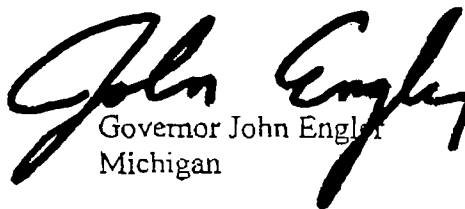
Governor Roy Barnes
Georgia



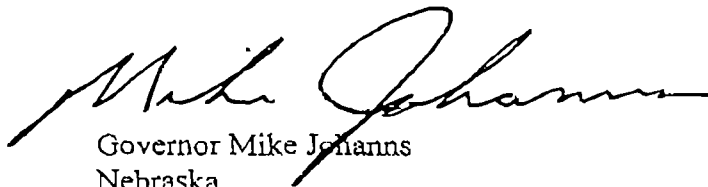
Governor George H. Ryan
Illinois



Governor Tom Vilsack
Iowa



Governor John Engler
Michigan



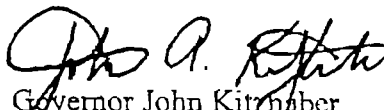
Governor Mike Johanns
Nebraska



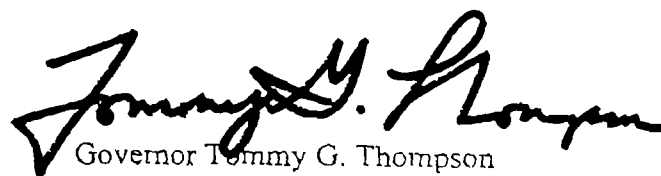
Governor Christine Todd Whitman
New Jersey

President Clinton
June 19, 2000
Page 3


Governor George E. Pataki
New York


Governor John Kitzhaber
Oregon


Governor Don Sundquist
Tennessee


Governor Tommy G. Thompson
Wisconsin

cc: The Honorable Albert Gore, Vice President
The Honorable Arlen Specter, Chairman Senate L/HHS/ Ed Appropriations Committee
The Honorable Tom Harkin, Ranking Member Senate L/HHS/ Ed Appropriations Committee
The Honorable John Porter, Chairman House L/HHS/ Ed Appropriations Committee
The Honorable David Obey, Ranking Member House L/HHS/ Ed Appropriations Committee
The Honorable Donna Shalala, Secretary of U.S. Dept. of Health and Human Services

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 BILL LUTHER MINNESOTA
 LOIS CAPPE CALIFORNIA

U.S. House of Representatives Committee on Commerce

Room 2125, Rayburn House Office Building
 Washington, DC 20515-6115

DEMOCRATIC STAFF

JAMES H. HARRIS, CHIEF OF STAFF

FAX COVER SHEET

DATE:

6/20/2000

TO:

Chris Jennings

FROM:

Jenna Bendure of US, Geneticis Fellow

FAX NUMBER:

456-5557

NUMBER OF PAGES:

(Including Cover)

6

COMMENTS:

Because of the White House's
 long-standing concern about banning
 genetic discrimination in insurance & employment,
 we thought the following correspondence - esp.
 Mr. Bliley's 6/1 letter, would be of interest.
 Also, FBI, flyer on a press conf. Wed AM.

(If there are problems with this transmission,
 please phone 202-226-3400, Democratic Staff, 564 FHOB.)

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BILL LUTHER, MINNESOTA
LOIS CAPPS, CALIFORNIA

U.S. House of Representatives
Committee on Commerce
Room 2125, Rayburn House Office Building
Washington, DC 20515-6115

June 1, 2000

JAMES E. DERDERIAN, CHIEF OF STAFF

The Honorable John Dingell
U.S. House of Representatives
2328 Rayburn House Office Building
Washington, DC 20515

Dear John:

Thank you for your letter requesting hearings on genetic nondiscrimination.

According to the *Washington Post*, Philip Reilly, a medical geneticist and Executive Director of the Eunice Kennedy Shriver Center in Waltham, Massachusetts, said in years of studying the issue he has yet to see a clear-cut case of discrimination. "There is extremely little evidence to support this as a realistic threat."

As you know, there are few legislative days in which we can accomplish the Committee's goals for the year. I think that this is a very interesting issue to explore as time permits.

Sincerely,



Tom Bliley
Chairman

TB: mw

Congress of the United States

Washington, DC 20515

February 2, 2000

The Honorable Thomas J. Bliley, Jr.
Chairman
House Committee on Commerce
2125 Rayburn Office Building
Washington, D.C. 20515

Dear Chairman Bliley,

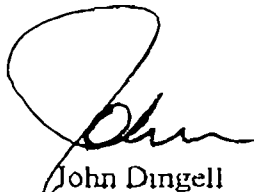
As genetic research races ahead, the Commerce Committee has an obligation to examine the policy implications of these advances. Accordingly, we urge you to hold a hearing on legislation to ban genetic discrimination in health insurance.

Perhaps no issue in genetics is more pressing or controversial than genetic discrimination. Anecdotal evidence of genetic discrimination already exists. In addition, the fear of discrimination is leading Americans to avoid both genetic tests and genetic research trials. Our constituents are denying themselves access to valuable health information because Congress has failed to ensure that this information cannot be used against them.

In particular, we would like to draw your attention to two bills introduced by our colleague from New York, Rep. Louise Slaughter. H.R. 306, the Genetic Information Nondiscrimination in Health Insurance Act, and H.R. 2457, the Genetic Nondiscrimination in Health Insurance and Employment Act, each address critical issues surrounding genetic discrimination. H.R. 306 enjoys the support of 212 bipartisan cosponsors and over 100 health-related organizations. Similarly, H.R. 2457 is supported by Democrats, Republicans and outside advocacy groups alike. The high level of interest in these bills demonstrates our colleagues' keen interest in protecting our constituents against genetic discrimination.

Congress's failure to address this issue is jeopardizing the future of genetic research, as well as hindering utilization of cutting edge genetic health care services. Moreover, as the Human Genome Project continues to elucidate genetic predispositions to common chronic health problems, few Americans will be spared the potential for genetic discrimination in health insurance. For these reasons, we strongly urge you to hold a hearing on genetic discrimination promptly.

Sincerely,



John Dingell
Member of Congress



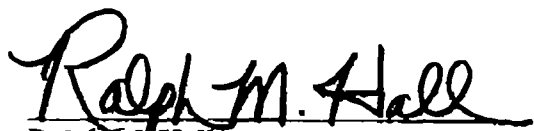
Sherrod Brown
Member of Congress



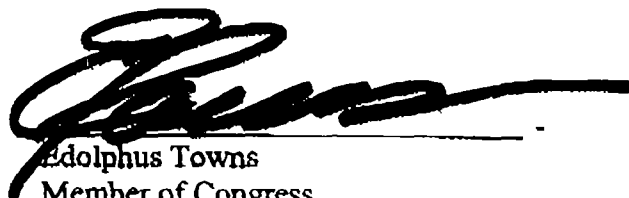
Henry A. Waxman
Member of Congress



Edward J. Markey
Member of Congress



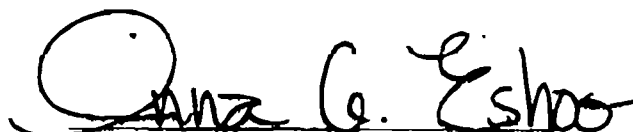
Ralph M. Hall
Member of Congress



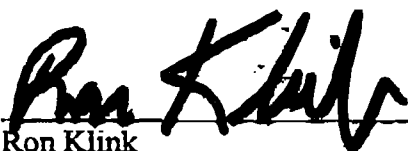
Edolphus Towns
Member of Congress



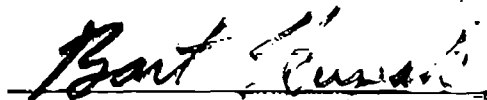
Frank Pallone, Jr.
Member of Congress



Anna G. Eshoo
Member of Congress



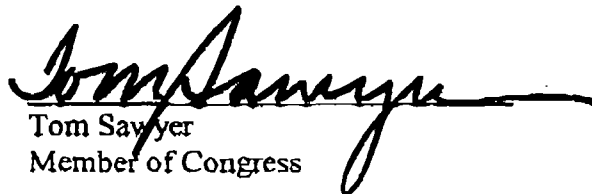
Ron Klink
Member of Congress



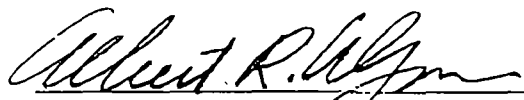
Bart Stupak
Member of Congress



Eliot L. Engel
Member of Congress



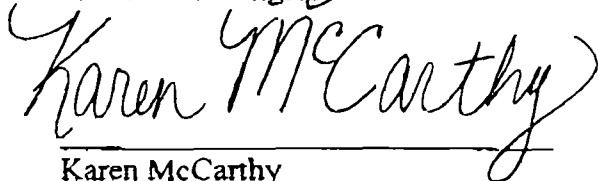
Tom Sawyer
Member of Congress



Albert R. Wynn
Member of Congress



Gene Green
Member of Congress

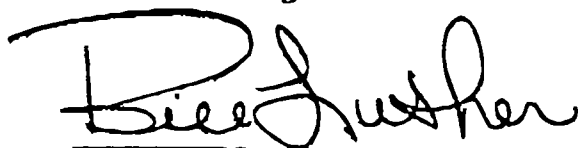


Karen McCarthy
Member of Congress



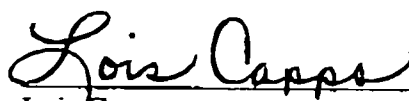
Ted Strickland
Member of Congress


Diane DeGette
Member of Congress


Bill Luther
Member of Congress


Bobby Rush
Member of Congress


Thomas M. Barrett
Member of Congress


Lois Capps
Member of Congress

Office of Science & Technology Policy
(OSTP)

FAX



Date:

Number of pages including cover sheet:

2

To:

Chris JENNINGS

Phone:

Fax phone:

65557

CC:

Phone:

From:

Rich Kastro

424 Old Executive Office Building
Washington, D.C. 20502

Phone:

202-456-7116

Fax phone:

202-456-6021

REMARKS:

☐ Urgent

☐ For your review

☐ Reply ASAP

☐ Please comment

OSTP Comments on Draft Executive Order

Thank you for the opportunity to provide comments on the draft Executive Order to Prohibit Discrimination in Federal Employment Based on Protected Genetic Information. OSTP is pleased that the Executive Order is close to final agreement and hopes that it can be announced very soon. One possible venue is the annual meeting of the Genome Action Coalition, which has invited the President to appear as the keynote speaker. The meeting is scheduled for February 1, but there may be some flexibility to move it to February 2.

The first comment is that the title needs to be changed to read "Protected" instead of "Predictive." Other comments are as follows:

1-201(b) - the first "or" in the next to last line should be deleted.

1-201(e)(1)(C) - it was agreed at the Tuesday meeting that the term "condition" would be added, as has been done later in section 1-301(a). We would prefer to use "medical condition" or delete "condition" altogether to avoid confusion.

1-301(a)(2) and (3) - add "medical" as a qualifier for "condition."

1-301(a) - there ought to be a provision that prevents such information from being disclosed by the evaluator to anyone other than the applicant/employee.

1-301(a)(3) - we need to expand on "applicant" by inserting "employee" as the E.O. also guides post-employment practices.

1-301(c)(2) and (3) - something doesn't follow here - the employee needs to be told that the information exists, but he/she may not want to have the results. There must be notification of the availability of the information and opportunity provided to get it. The consent, then, precedes obtaining the genetic information.

1-402(d) - was supposed to have been deleted.

Senate Bill: Title III Genetic Information and Services

The Senate provisions on the use of genetics in insurance are conceptually similar to what the Administration and the minority staff (Daschle/Slaughter) drafted last year, but there are significant differences in the details.

The primary differences:

- 1. There is no disclosure restriction.** Instead, the Senate bill would require plans to have a confidentiality policy and make it available. (The confidentiality requirements in the Senate bill and Administration draft are the same.)
- 2. The enforcement mechanism is inadequate.** The genetics provisions are drafted as amendments to HIPAA, and therefore, the HIPAA enforcement remedies apply. The HIPAA enforcement tools are generally weak, but they are particularly inappropriate for genetics discrimination (i.e., the Public Health Service Act and ERISA provisions do not have remedies appropriate to the nature of an illegal use of genetics information). The Daschle/Slaughter bill (S.1322) would permit private right of action of legal and equitable relief, as well as enhanced civil monetary penalties for violations of the genetics provisions.
- 3. Definitions.** There are differences in the definition of what constitutes genetic information and testing. We believe the Administration definition is more precise in both its inclusion and exclusion of what is covered, and thus would be subject to less judicial misinterpretation of the statute's intent. (Other definitions are the same.)
- 4. Preemption.** The Senate bill would generally preempt most state laws in this area because of the ERISA preemption. The Daschle bill would explicitly not preempt state laws that are more protective of individual rights.

The Slaughter amendment to HR 2723 is very weak compared to the Daschle/Slaughter bill. It is much more limited in its restriction on collection, disclosure and scope of definitions.

Comparison of Genetic Discrimination Provisions

Bill	S. 1322/ H.R. 2457 Daschle/Slaughter	H.R. 306 Slaughter	S. 1344 Nickles
definition of genetic information	- genetic tests of individual or family (includes gene products) - family history - excludes current health status and sex	- genes - gene products - family history	if asymptomatic: - genetic tests of individual or family (includes gene products) - family history - excludes current health status and sex
remedies	-full private right of action -Secretary may seek CMPs of \$50,000 for first violation, \$100,000 for subsequent violations	-full private right of action	-ERISA: equitable relief -PHA: (up to \$100/day if federal enforcement of HIPAA) -IRC: excise taxes of up to \$100/day
markets covered	ERISA PHA group PHA individual Medigap	ERISA PHA group PHA individual Medigap	ERISA PHA group PHA individual
prohibition on enrollment restrictions on basis of g.i.	✓	✓	✓
prohibition on adjusting premiums on basis of g.i.	✓	✓	✓
prohibition on requesting/requiring genetic testing	✓	—	—
prohibition on requesting/requiring genetic information	✓	✓	✓
prohibition on collecting/purchasing genetic information	✓	—	no prohibition on purchasing

prohibitions on disclosure of g.i.	health insurer may not disclose without consent to other insurer, employer, MIB, or other entities specified by Secretary	every disclosure to any entity requires consent each time and identification of recipient	confidentiality plan required
prohibitions on employment discrimination on basis of g.i.	✓	—	—

From: SARAH SCHOENECKER
To: LISA ROVIN
Date: 12/2/99 9:16AM
Subject: Re: genetic discrimination

Attached is Steve's summary and side by side. The Daschle/Slaughter bill is the Administration supported bill.

Basically the Senate version is weak on enforcement (current ERISA remedies apply), does not prohibit plans from requesting or requiring genetic information or tests (although they cannot condition enrollment on the tests), does not prevent the purchase of genetic information, and only requires plans to have a confidentiality procedure, rather than detailing prohibited disclosures.

In addition, it does not prohibit employment discrimination on the basis of genetic information and my understanding is that the protections only apply if the person is asymptomatic.

Steve, is this accurate?

>>> LISA ROVIN 12/02/99 09:02AM >>>

Yes, and also tell me the gist.

>>> SARAH SCHOENECKER 12/02/99 08:52AM >>>

It did and we didn't. I think Steve did a side by side comparing it with the bill we do support. I can send it to you if you would find it useful.

>>> LISA ROVIN 12/01/99 04:35PM >>>

Did the senate PBOR have genetic discrimination language? Did we like it?

CC: sfinan

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003. note	re: phone number (1 page)	n.d.	P6/b(6)

COLLECTION:

Clinton Presidential Records
Domestic Policy Council
Devorah Adler
OA/Box Number: 20146

FOLDER TITLE:

Genetic Discrimination [Folder 3]

2012-0463-S

rc757

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

- P1 National Security Classified Information [(a)(1) of the PRA]
- P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
- P3 Release would violate a Federal statute [(a)(3) of the PRA]
- P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
- P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [(a)(5) of the PRA]
- P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

C. Closed in accordance with restrictions contained in donor's deed of gift.

PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).

RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

- b(1) National security classified information [(b)(1) of the FOIA]
- b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
- b(3) Release would violate a Federal statute [(b)(3) of the FOIA]
- b(4) Release would disclose trade secrets or confidential or financial information [(b)(4) of the FOIA]
- b(6) Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA]
- b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
- b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
- b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

CENTRAL INTELLIGENCE AGENCY

WASHINGTON, D.C. 20505

Office of General Counsel

2 March 1999

Via Facsimile

Mr. Mac Reed
Office of the General Counsel
Executive Office of the President
Office of Management and Budget
Washington DC 20503

Dear Mr. Reed:

I am responding on behalf of the Central Intelligence Agency to Proposed Executive Order Entitled "To Prohibit Discrimination in Federal Employment Based on Predictive Genetic Information". While this Agency does not object to the stated prohibition, we have a concern with one portion of the definition of predictive genetic information.

The definition section of the proposed Executive Order states, in pertinent part, that:

(1) In general, predictive genetic information means—

(A) information about an individual's genetic tests;

(B) information about genetic tests of family members of the individual; or

(C) information about the occurrence of a disease or disorder in family members of the individual.

1-301(f)(1). Definitions.

Our concern is specifically targeted to 1-301(f)(1)(C): "information about the occurrence of a disease or disorder in family members of the individual", for the following reasons.

Agencies with employees who serve overseas in a career capacity collect medical histories that include family history. This is a standard medical practice in these agencies for the purpose of determining an individual

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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
004. letter	To: Mac Reed re: Exectuive Order (partial) (1 page)	03/02/1999	P3/b(3)

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Devorah Adler
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2012-0463-S

rc757

RESTRICTION CODES

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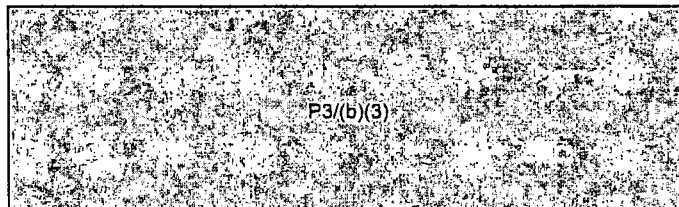
Mr. Mac Reed

employee's risks of disease while on assignment overseas. In particular, since a family history of premature heart disease is a strong predictor of heart disease in the individual, it is critical information for overseas assignments. Other examples include certain cancers, diabetes, depression and alcoholism. Each of these disorders are linked to an individual's genetic makeup. Agencies who assign employees overseas require this information to make assignments of individuals to areas with appropriate medical resources. Employees with this type of risk history are not automatically precluded or excluded from overseas assignments. Rather, the family history combined with the employee's current health status may necessitate an assignment to an area with particular available health services to ensure adequate care for the employee should it be necessary.

We have two proposals that would alleviate our concerns in this area. First, the Executive Order could be amended to provide an exception for agencies who assign employees overseas. Specifically, Section 1-401 could be amended to include a new sub-paragraph (d) that states "The employing department or agency may collect predictive genetic information with respect to an employee to determine whether that employee is medically fit to serve overseas." Second, Section 1-301(f)(1)(C) could be deleted. This would allow those agencies with overseas employees to continue to gather information directly relevant to the employee's potential assignment, but protect the employee from discrimination based on non-standard tests.

I look forward to discussing with you how our concerns can be best resolved.

Sincerely,



P3(b)(3)

[004]



United States Department of State

Medical Director
Department of State and the Foreign Service

Washington, D.C. 20520

March 12, 1999

VIA FACSIMILE

Mac Reed, Esq.
Office of the General Counsel
Executive Office of the President
Office of Management and Budget
Washington, D.C. 20503

Proposed Executive Order Entitled
"To Prohibit Discrimination in Federal Employment Based
On Predictive Genetic Information"

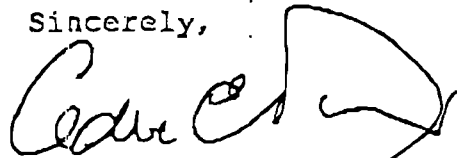
Dear Mr. Reed:

We are responding to the alternative language for section 1-403 of the proposed Executive Order put forward by the Central Intelligence Agency regarding the collection and use of predictive genetic information in connection with making an employment or overseas assignment decision consistent with applicable law. Although we have no objection to that language, the Office of Medical Services (MED) of the Department of State does not utilize predictive genetic information as defined in the proposed Executive Order in making medical clearance decisions either on a pre-employment or on an in-service basis. On the other hand, the ability to collect, retain and utilize information about the occurrence of a disease or disorder in family members of an individual--i.e., "family history"--is critical to MED's ability to render ongoing health care to employees and their family members who are covered by the Department of State medical program mandated under Section 904 of the Foreign Service Act of 1980, as amended. Without family history, a medical practitioner cannot assess the risks to an individual of developing various medical conditions or illnesses, and therefore cannot adequately advise a patient about necessary health maintenance and prophylactic measures. In the context of the Foreign Service, the lack of such information would seriously impair MED's ability to advise patients about the availability of relevant medical services at various posts.

Accordingly, if the proposed Executive Order is to be signed, we strongly urge that it be modified to permit the collection, retention and use of family history information for the purposes of providing ongoing health care and health maintenance advice. To that end, we have attached a proposed revision to the language submitted by the CIA. Alternatively, the exceptions set forth in section 1-301 of the proposed Executive Order should be revised to permit family history information to be collected, retained and used by an agency that provides health care services for that purpose only.

Please feel free to call me at (202) 663-1611 if you have any questions about our concerns.

Sincerely,



Cedric E. Dumont
Medical Director

Attachment:

As stated.

First, employment discrimination is very subtle and very hard to prove. If you can't get a job in the first place, it's almost impossible to prove that your genetic fingerprint is the cause.

✓
employment
Let me tell you about Richard, not his real name of course: Richard is an experienced engineer living in the southwest with years of excellent performance records. After interviewing successfully for a lucrative position and receiving a tentative offer, he was told to go for a routine, pre-employment medical exam. When Richard returned, the interviewer took him aside and showed him the medical report, which correctly diagnosed him with Klinefelters -- a common chromosome disorder occurring approximately one in 450 male births. Klinefelters, like many genetic disorders, looks the same in a laboratory test but has tremendous range of expression. In the past the diagnosis was incorrectly associated with mental retardation and serious psychiatric problems. Richard had an excellent work history however the employer refused to hire him based on misunderstanding the real implications of the diagnosis for Richard's long-range productivity and health care costs. Richard was told that the offer was being withdrawn. If he protested, the company would deny that the conversation ever took place.

Second, if you're laid off a job, the reasons are not on public record and can be justified by various and complex reasons relating to business necessity.

employment
Let me tell you about Kim: Kim is a social worker who worked within a large human services agency. During a staff workshop on caring for people with chronic illnesses, Kim shared that she was the primary caretaker for her father chance of developing this fatal neurological condition. She had never even seriously considered having the test to confirm whether or not she received the positive gene from her mother. One week after revealing her risk status based on family history, Kim was fired from her job -- despite outstanding performance reviews in the months prior to the firing. Note that Kim was healthy, had never had a genetic test, had no clinical diagnosis and an unblemished work history. She had no idea that her voluntary disclosure might affect her employment.

People like Kim and Richard say they simply don't know where to go with their complaints and can't afford legal fees. More importantly they don't want to make their genetic inheritance even more public and put their families and their futures at further risk. Chances are strong that we are actually seeing a significant under-reporting of the problem.

Third, individuals commonly report that major life decisions -- with respect to type of work, job change, moving or changing health care plans -- are made anticipating discrimination. We know that some consumers avoid genetic testing to safeguard their employment and their families medical insurance, sometimes at the risk of their own health.

✓
Seeking Job
Let me tell you about John: John's mother and brother -- both recently identified with Hereditary Hemochromatosis-- strongly urged him to be tested. John was in his early thirties and could clearly benefit from earlier detection of HH. Understood only in the last several years, this is one of the most commonly inherited genetic diseases and occurs approximately one in 330 Caucasians. Early detection and diagnosis are everything. Otherwise lead toxicity builds insidiously and compromises various organ systems, causing diffuse, chronic symptoms and eventual death. The good news is that HH is simple and inexpensive to treat; regular phlebotomies or blood letting, keep lead levels within normal range. Genetic tests and early detection can provide both employee and employer with invaluable information to increase the odds of a normal, healthy, productive work life. The alternative -- not testing because of fear of genetic discrimination -- can cost employers and insurance companies considerable health care dollars and an employee literally their life.

In this real life story, John chose not to be tested. He didn't have health insurance at the time and was worried about being uninsurable and unemployable if he were to test positive and have test results on his medical record at the time of a job search the following year.

Are these individuals over-reacting? Remember that fear of adverse consequences is very real, palpable, intense and certainly has clear historical roots in what happened with the Sickle Cell Anemia Control Act. Consider further that if these same worries scare people from participating in research studies, we won't ever see the great promise and potential of today's genetic discoveries.

Fourth, The Alliance of Genetic Support Groups understands that employers and insurance companies need to think carefully about long-range employee productivity and health care costs.

However genetic science and medicine are not yard-stick technologies with linear implications. Genetic test results are not black and white, yes or

know, x years of productivity or x dollars of health care costs or x % of employment risk. Most genetic diseases do manifest with wide and unpredictable variability of expression -- from the most mild with almost no symptoms or associated functional limitations or health care costs to the most severe with, of course, associated limitations in productivity and expensive health care costs. Two genetic fingerprints can look the same in a petri dish; associated productivity and health care costs can be drastically different.

Genetic test results must not be used arbitrarily to target individuals at risk, narrowing futures before they begin and wasting potential for productive, autonomous lives.

The irony is that employers stand to deprive themselves of skilled, experienced and productive workers. A genetic diagnosis does not necessarily mean less productivity and more health care dollars for employers. In the case of some more common genetic conditions -- HH and some cancers for example -- early detection can actually save tremendously in productivity, health care dollars and human heart ache by preventing the damaging effects of the disease itself.

Fifth, in a few years, when we will all be identified with our own particular family risk or predisposition or susceptibility, arbitrary targeting will make no sense at all. Employers, owners, human resource personnel, CEOs are all ultimately as vulnerable as the rest of us. After all, we all possess imperfect genetic inheritances that will be transparent with tomorrow's technologies.

Last, the impact of genetic discrimination must be measured in terms of even broader societal costs. Genetic discrimination threatens to create an underclass of citizens who are uninsurable and unemployable, at enormous public financial and moral cost.

✓ *seeking work*

Let me tell you about Carole and her daughter Tracy: Carole called the Alliance helpline for help in attaining employment and medical insurance coverage for herself and her daughter. Carole lives in a close-knit community in the northwest where her husband ran a local store and was well appreciated for his neighborly spirit. Several years ago her husband died of cardiac problems associated with Marfan Syndrome. Their daughter, is six years old, has Marfan syndrome and likely will require heart surgery in the future. Fortunately Carole's family and in-laws have done everything possible to help their granddaughter and her. They share Carole's increasing concern that her

daughter's condition will prevent her from securing employment and health insurance for the two of them. Carole appreciates her family's financial and emotional support but wants to get on with her new life and family situation. However Carole is facing a most sobering, heart-wrenching and intolerable but possible alternative: to agree to her sister and brother-in-law's offer to adopt her daughter and put her on their health insurance plan. What kind of society forces a mother to give up her daughter so that she obtains the medical care she needs to survive?

Let me tell you about Lisa and her son Jonathan: Lisa suspected that her young first grader, Jonathan, had learning disabilities. Her doctor performed some tests and concluded that Jonathan has Fragile X Syndrome, an inherited form of mental retardation. Lisa, like most of us, had insurance through her employer. Claiming that his diagnosis qualified as a pre-existing condition, the insurance company eliminated Jonathan's health coverage. Lisa searched -- without success -- for another company that would employ her and insure her son. Ultimately she was forced to quit her job and become unemployed to qualify for Medicaid and get Jonathan covered at public expense. Does this make any financial or moral sense?

Nearly 30 years have passed since the sickle cell tragedies. But we have not yet succeeded in making the public fully aware of these critical legal, social and ethical issues. In truth we are all still illiterate in the language and logic of genetics.

This is a problem that will grow larger and larger over the next few years. Right now we can test for a handful of genes but that number will grow to the thousands. These future tests will predict risk of more common diseases and susceptibility to more common health problems. Given the likelihood that each of us carries 5 to 7 mutated genes, we are all at risk for genetic discrimination. We could all be vulnerable to the misuse of genetic information and exclusion from jobs, health care, education and other life opportunities.

These wonderful and inspiring scientific advances have accelerated the need for federal protections. The Alliance of Genetic Support Groups calls for the unequivocal prohibition of all kinds of genetic discrimination, including employment, health insurance and education.

Withdrawal/Redaction Marker

Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
005. letter	To: Mac Reed re: Exectuive Order (partial) (1 page)	03/11/1999	P3/b(3)

COLLECTION:

Clinton Presidential Records
Domestic Policy Council
Devorah Adler
OA/Box Number: 20146

FOLDER TITLE:

Genetic Discrimination [Folder 3]

2012-0463-S

rc757

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

- P1 National Security Classified Information [(a)(1) of the PRA]
- P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
- P3 Release would violate a Federal statute [(a)(3) of the PRA]
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- P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [(a)(5) of the PRA]
- P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

C. Closed in accordance with restrictions contained in donor's deed of gift.

PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).

RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

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- b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
- b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
- b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

MAR-11-1999 17:33
MAR 11 1999 17:33

OMB GC

202 395 7289 P.02/03

CENTRAL INTELLIGENCE AGENCY

WASHINGTON, D.C. 20505

Office of General Counsel

11 March 1999

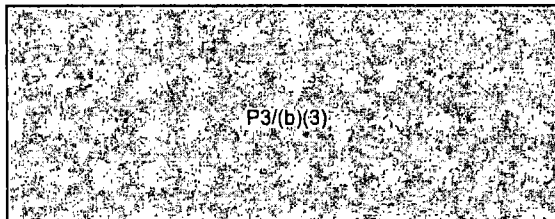
Via Facsimile

Mr. Mac Reed
Office of the General Counsel
Executive Office of the President
Office of Management and Budget
Washington, D.C. 20503

Dear Mr. Reed:

As we discussed last evening, attached is the language that we believe cures the concerns we raised at the meeting regarding the proposed Executive Order Entitled "To Prohibit Discrimination in Federal Employment Based on Predictive Genetic Information". Please circulate this language appropriately. Thank you, in advance.

Sincerely,



[005]

Enclosure:
As stated

1-403. An agency head may:

(a) determine that the collection of protected genetic *not just from history* information is required from an individual, after a conditional offer of employment is made, or in the course of employment, when the collection of such protected genetic information is job-related and consistent with applicable law; and

(b) determine that the use of such protected genetic information is necessary in connection with making an employment or overseas assignment decision consistent with the applicable law.

1-403. An agency head may:

(a) determine that the collection of protected genetic information is required from an individual, after a conditional offer of employment is made, or in the course of employment, when the collection of such protected genetic information is job-related and consistent with applicable law; and

(b) determine that the use of such protected genetic information is necessary in connection with making an employment or overseas assignment decision consistent with the applicable law.

Insert for 1-403 (a) after the word "job-related": "or related to the provision of health care services by or on behalf of the agency to such individual"

Insert for 1-403(b) after the phrase "overseas assignment decision": "or the provision of health care services by or on behalf of the agency"



U.S. EQUAL EMPLOYMENT OPPORTUNITY COMMISSION
Washington, D.C. 20507

Office of
the Chairwoman

March 12, 1999

VIA FACSIMILE

Mr. Mac Reed
Office of the General Counsel
Executive Office of the President
Office of Management and Budget
Washington, D.C. 20503

Dear Mr. Reed:

The Equal Employment Opportunity Commission (EEOC) has reviewed the Central Intelligence Agency's (CIA) proposed language for section 1-403 of the proposed Executive Order prohibiting discrimination in federal employment on the basis of protected genetic information. The Commission's basic position is that no new exception should be included in the Executive Order, and that any exception that is included should reflect the language proposed by the Commission earlier this week. The EEOC has the following specific comments on the CIA's proposed language:

- (1) The proposed language does not require agencies to consult with the Department of Health and Human Services (HHS) and the EEOC before determining that the broad exception applies. The Commission believes that such consultation is necessary.
- (2) The EEOC believes that the exemption allowing the collection of protected genetic information from applicants at the post-offer stage and from employees where such collection is "job related and consistent with applicable law" is too broad. The standard actually provides less protection to *employees* than the Rehabilitation Act. The Rehabilitation Act allows employers to collect medical information from employees only where such information is "job-related and *consistent with business necessity*."
- (3) Subpart b of the proposed exception is also too broad. It allows any employing department or agency to use protected genetic information where "necessary in connection with making an *employment decision* or overseas assignment decision consistent with the applicable law" (emphasis added). It is unclear whether the terms "necessary" and "consistent with the applicable law" are intended to incorporate the

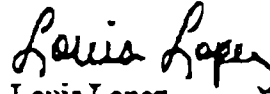
Letter to: Mr. Reed
March 12, 1999
Page 2

Rehabilitation Act's "direct threat" (i.e., significant risk of substantial harm) standard. The Commission thinks that this standard should be referenced specifically. If the intent is for the "direct threat" standard to apply to any employment decision, there should be no need to reference overseas assignments specifically, as it is a type of employment decision. If, however, the intent here is *not* to incorporate the "direct threat" standard, the effect of this language would be to broadly exempt any employment decision by the CIA from "direct threat" analysis, not just overseas assignment decisions. The EEOC would object strongly to such a broad-based exemption.

- (4) Inclusion of the CIA's proposed exemption language would undermine current congressional efforts to craft genetic discrimination legislation for the private sector that does not include broad exemptions for data collection and employment decisions. Many private sector employers would want exemption language like that proposed by the CIA, and could be expected to advocate for such language with Congress.

Please feel free to contact me at (202) 663-4098 to discuss these comments.

Sincerely,



Louis Lopez

Special Assistant to the Chairwoman



United States Department of State

*Medical Director
Department of State and the Foreign Service*

Washington, D.C. 20520

January 14, 2000

VIA FACSIMILE
(202) 456-5557

Christopher C. Jennings
Deputy Assistant to the President for Health Policy
216 Old Executive Office Building
Washington, D.C. 20502

Proposed Executive Order Entitled "To Prohibit Discrimination in Federal
Employment Based on Predictive Genetic Information"

Dear Mr. Jennings:

We have reviewed the draft of the proposed Executive Order regarding protected genetic information dated January 11, 2000, at 5:00 p.m. We think that there are a few areas in the Executive Order that should be clarified to make explicit what we understand to be the intention of the latest revisions and to avoid any subsequent misinterpretation of the current language.

1. Family history information obtained under 1-301(a) needs to be available for treatment, payment and health care operations, but would seem to be barred by the use of the word "exclusively" in 1-301(a)(2). Similarly, although 1-301(b)(3) permits the disclosure of the results of genetic services performed for employees for purposes of treatment, payment, or health care operations, there is no comparable provision permitting disclosure for treatment purposes of such information that might be obtained about applicants who actually become employees. We also suggest that the term "health care operations" used in 1-301(b)(3) should be defined.
2. There is still some ambiguity in the proposed Executive Order about its applicability to protected genetic information obtained from family members, such as in connection with medical clearance decisions about them. We suggest that there be a statement clarifying the scope of the proposed Executive Order in that respect. 1-202(d) should also be revised so that it can no longer be read to prevent the disclosure to family member of protected genetic information about

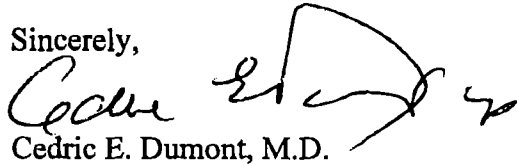
them (while presumably permitting the disclosure of such information to the employee).

3. The nondiscrimination requirements in 1-202(a) and (b) prohibiting agencies from taking certain actions against employees "because of" protected genetic information should not be read to prevent an agency from taking otherwise lawful actions on the basis of information obtained from medical evaluations. That is, if medical evaluations performed because of an applicant's family history indicate the presence of a current disease, disorder or condition, the agency should not be constrained in its actions on the grounds that the reason for undertaking the medical evaluation was protected genetic information. We think that it would be useful to state this point clearly.

In addition, I want to state our understanding that this Executive Order would not prevent the Office of Medical Services, using information obtained through a family history (i.e. family history of anemia), from testing for the presence of hemoglobinopathies such as sickle cell disease/trait or thalassemia and acting on the basis of the results of those tests.

We appreciate your efforts to take our programmatic concerns into account in drafting the Executive Order.

Sincerely,

A handwritten signature in black ink, appearing to read 'Cedric E. Dumont', followed by a large, stylized flourish or checkmark.

Cedric E. Dumont, M.D.

EXECUTIVE ORDER

TO PROHIBIT DISCRIMINATION IN FEDERAL EMPLOYMENT
BASED ON PREDICTIVE GENETIC INFORMATION

By the authority vested in me as President of the United States by the Constitution and the laws of the United States of America, it is ordered as follows:

**Nondiscrimination in Federal Employment on the Basis of
Protected Genetic Information**

1-101. It is the policy of the Government of the United States to provide equal employment opportunity in Federal employment for all qualified persons and to prohibit discrimination against employees based on protected genetic information or information about a request for or the receipt of genetic services.

This policy of equal opportunity applies to every aspect of Federal employment.

1-102. The head of each Executive department and agency shall extend the policy set forth in Section 1-101 for all its employees covered by Section 717 of Title VII of the Civil Rights Act of 1964 as amended.

1-103. Executive departments and agencies shall carry out the provisions of this order to the extent permitted by law and consistent with their statutory and regulatory authorities and their enforcement mechanisms. The Equal Employment Opportunity Commission shall be responsible for coordinating the policy of the Government of the United States to prohibit discrimination against employees in Federal employment based on protected genetic information or information about a request for or the receipt of genetic services.

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Requirements Applicable to Employing Departments and Agencies

1-201. Definitions.

- (a) The term "employee" shall include an employee, applicant for employment, or former employee covered by Section 717 of the Civil Rights Act of 1964 (42 U.S.C. 2000e-16).
- (b) Genetic monitoring means the periodic examination of employees to evaluate acquired modifications to their genetic material, such as chromosomal damage or evidence of increased occurrence of mutations, that may have developed in the course of employment due to exposure to toxic substances in the workplace, in order to identify, evaluate, or respond to the effects of, or control, adverse environmental exposures in the workplace.
- (c) Genetic services means health services, including genetic tests, provided to obtain, assess, or interpret genetic information for diagnostic or therapeutic purposes, or for genetic education or counseling.
- (d) Genetic test means the analysis of human DNA, RNA, chromosomes, proteins, or certain metabolites in order to detect disease-related genotypes or mutations. Tests for metabolites are covered when an excess or deficiency of the metabolite indicates the presence of a mutation or mutations.
- (e) Protected genetic information.
 - (1) In general, protected genetic information means--
 - (A) information about an individual's genetic tests;
 - (B) information about genetic tests of family members of the individual; or

(C) information about the occurrence of a disease or disorder in family members of the individual.

- (2) Information about an individual's current health status (including information about sex, age, physical exams, and chemical, blood, or urine analyses of the individual) is not protected genetic information unless it is described in subparagraph (1).

1-202. The agencies, in discharging their responsibilities under this order, shall implement the following nondiscrimination requirements.

- (a) The employing department or agency shall not discharge, fail or refuse to hire, or otherwise discriminate against any employee with respect to the compensation, terms, conditions, or privileges of employment of the employee, because of protected genetic information with respect to the employee or because of information about a request for or the receipt of genetic services by such employee or by a family member of such employee.
- (b) The employing department or agency shall not limit, segregate, or classify employees in any way that would deprive or tend to deprive any employee of employment opportunities or otherwise adversely affect the employee's status, because of protected genetic information with respect to the employee or because of information about a request for or the receipt of genetic services by such employee or by a family member of such employee.
- (c) The employing department or agency shall not request, require, collect, or purchase protected genetic information with respect to an employee or a family member of the employee or information about a request for or the receipt of genetic services by such employee or by a family member of such employee.
- (d) The employing department or agency shall not disclose protected genetic information with respect to an employee or information about a request for or the receipt of genetic services by an employee or by a family member of an employee except --

- (1) to the employee who is the subject of the information, at the request of that employee to whom disclosure is being made;
 - (2) to an occupational or other health researcher if the research is conducted in compliance with the regulations and protections provided for under part 46 of title 45, Code of Federal Regulations;
 - (3) under legal compulsion of a Federal court order, except that if the court order was secured without the knowledge of the individual to whom the information refers, the employer shall provide the individual with adequate notice to challenge the court order unless the court order also imposes confidentiality requirements; and
 - (4) to government officials investigating compliance with this Executive Order if the information is relevant to the investigation.
- (e) The employing department or agency shall not maintain protected genetic information or information about a request for or the receipt of genetic services in general personnel files; such information shall be treated as confidential medical records, and kept separate from personnel files.

Exceptions

1-301. The following exceptions shall apply to the nondiscrimination requirements set forth in Section 1-202.

- (a) The employing department or agency may request, require, collect, or purchase protected genetic information with respect to an employee or any information about a request for or receipt of genetic services by such employee or by a family member of such employee if:

- (1) the employee or family member uses genetic or health care services provided by the employer;
 - (2) the employee or family member who uses the genetic or health care services has provided prior, knowing, voluntary, and written authorization to the employer to collect protected genetic information;
 - (3) the person who performs the genetic or health care services does not disclose the results of the genetic services to anyone except to the employee who uses the services, and pursuant to section 1-202(d) of this order; *and*
 - (4) such information is not used in violation of Sections 1-202(a) or 1-202(b) of this Executive Order.
- (b) Genetic monitoring of biological effects of toxic substances in the workplace shall be permitted if all of the following conditions are met:
- (1) the employee has provided prior, knowing, voluntary, and written authorization;
 - (2) the employee is informed of the specific results of the monitoring;
 - (3) the employee is informed of any other protected genetic information that may have been acquired, provided that the employee has given prior, knowing, voluntary, and written consent to such additional disclosure;
 - (4) the monitoring conforms to any genetic monitoring regulations that may be promulgated by the Secretary of Labor; and

- (5) the employer, excluding any licensed health care professionals that are involved in the genetic monitoring program, receives results of the monitoring only in aggregate terms that do not disclose the identity of specific employees.
- (c) This Executive Order does not limit the statutory authority of a Federal agency to (1) promulgate or enforce workplace safety and health laws and regulations or (2) conduct or sponsor occupational or other health research that is conducted in compliance with regulations at part 46 of title 45, Code of Federal Regulations, (3) collect protected genetic information as a part of a lawful program, the exclusive purpose of which is to carry out identification purposes.

Miscellaneous

1-401. The head of each department and agency shall take appropriate action to disseminate this policy, and to this end shall designate a high level official responsible for carrying out its responsibilities under this Executive Order.

1-402. Nothing in this Executive Order shall be construed to:

(a) limit the rights or protections of an individual under the Rehabilitation Act of 1973 (29 U.S.C. 701 et seq.) or the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.), including coverage afforded to individuals under section 102 of Americans with Disabilities Act of 1990 and any other Federal statute;

(b) supercede any provision of the Privacy Act of 1974 (5 U.S.C. 552a), and actions taken under this Executive Order shall be in compliance with the Privacy Act.

(c) require specific benefits for an employee or dependent under the Federal Employees Health Benefits Program or similar program; or

(d) superceded any other statute, regulation, or rule that requires disclosure of information.

1-403. This order clarifies and makes uniform administration policy and does not create any right or benefit, substantive or procedural, enforceable at law by a party against the United States, its officers or employees, or any other person.

THE WHITE HOUSE

[DATE]

- ① fam med history
- ② work on long cons for Rehab Act
post emp. vs emp.
- ③ exception only covers
employee & families
are involved to

similar exceptions apply

WORKING GROUP DRAFT 12/21/99

OUP & NIH
edits on options

OPTION 3: ALLOWING ALL FORMS OF GENETIC INFORMATION TO BE COLLECTED BUT RESTRICTING USE TO MEDICAL EVALUATION OF CURRENT DISEASE AND PROHIBITING COLLECTION AS A CONDITION OF EMPLOYMENT

[1-201]

(e) Protected genetic information.

(1) In general, protected genetic information means--

(A) information about an individual's genetic tests;

(B) information about genetic tests of family members of the individual; or

(C) information about the occurrence of a disease or disorder in family members of the individual

(2) Protected genetic information does not include information, otherwise included in subparagraph (1), that is used ~~exclusively~~ to determine if further medical evaluation is needed to diagnose a current disease or disorder, provided that no individual may be required to furnish such information as a condition of employment,

OR as a condition
for promotion or
advancement

for treatment

Condition



"Hudson, Kathy (NHGRI)" <hudsonk@exchange.nih.gov>
01/05/2000 04:45:15 PM

Record Type: Record

To: Devorah R. Adler/OPD/EOP
cc: "Hudson, Kathy (NHGRI)" <hudsonk@exchange.nih.gov>, "Collins, Francis (NHGRI)" <francisc@exchange.nih.gov>
Subject: More Options

Devorah-

Thank you for sending the three options from Eddie Correia. NIH is concerned about making modifications to the definition of "protected genetic information" and would prefer a specific and narrow exception. The term "protected genetic information" and its definition in the E.O. are used in legislation regarding employment and health insurance and are almost becoming a term of art. Changing it now may create some problems and confusion. Specifically, in the health insurance context, the modifications to the definition would seem to be at odds with intent of those bills. Thus, we would like to propose the following. Please share this note with the group that met yesterday. We look forward to meeting tomorrow. Thanks,

Exceptions:

Insert as a new 301(a):

The employing department or agency may request, but not require, information defined in 1-201 (e)(1)(C) with respect to an applicant or employee that is used exclusively to assess if further medical evaluation is needed to determine an individual's fitness for duty in accordance with applicable law.

discussion questions from Peter S.

 Peter P. Swire
01/06/2000 12:18:27 PM

Record Type: Record

To: See the distribution list at the bottom of this message
cc:
bcc:
Subject: Re: draft e.o. on genetic discrimination 

Because I won't be able to attend this afternoon's meeting, I thought it might be useful to list the issues that I think people should be sure to make sure are well answered:

(1) There is a spectrum from an employer (a) requiring a test; (b) requesting a test; and (c) not being allowed to ask for a test. Gary Claxton said he might try to define a new category for (c).

(2) Is the definition of "protected genetic information" going to change from the draft? Despite NIH's concerns, the inclusion of family history in that definition is a major concern.

(3) Do we ever distinguish between family history and other sorts of protected genetic information? Perhaps without touching the actual definition of protected genetic information?

(4) How do we implement Eddie's idea of allowing use of protected genetic information for treatment (and therefore payment and health care operations)? Should there be some reference to the "substantial and direct risk" test?

(5) Are there any exceptions for space, intelligence activities, etc.? It seems we want to minimize these.

(6) Be sure to include the "treatment, payment, and health care operations" change.

Thanks,

Peter

Edward W. Correia

Edward W. Correia

01/06/2000 10:16:23 AM

Record Type: Record

To: Peter P. Swire/OMB/EOP@EOP

Withdrawal/Redaction Marker

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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
006. list	re: contact information (partial) (1 page)	03/10/1999	P3/b(3)

COLLECTION:

Clinton Presidential Records
Domestic Policy Council
Devorah Adler
OA/Box Number: 20146

FOLDER TITLE:

Genetic Discrimination [Folder 3]

2012-0463-S

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b(6) Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA]
b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

March 10, 1999

		P	F
MAC REED	OMA/OGC	395-3563	395-7294
*Rosemary Hart	DOJ/OLC	514-2027	514-0563
*Robin Lenhardt	DOJ/OLC	514-1762	514-0563
*Phil Breen	DOJ/Civ.Rts.	616-7526	307-1198
*Lisa Brown	OVP	456-9289	456-6429
*John Casciotti	DOJ/OGC (703)	697-9657	(703) 693-7616
*Eddie Correia	WM Council	456-2024	456-5055
Nancy Segal	EEOC (202)	663-4037	(202) 663-7101
Peggy Mastroianni	EEOC/OLC (202)	663-4609	(202) 663-7176
Pat Crawford	EEOC (202)	663-4012	663-7201

[006]

P3(b)(3)

Kevin Maroney	DOL	202/219-6141	202/219-5736
DANIEL T. MAGUIKE	DOL	202/219-8951	219-6531
Amy Turner	DOL	202/219-8671	219-7291
Nancy Howard	HHS	690-7450	
Stephen Finan	HHS	690-7387	401-7321
Bill Raeb	OASPE/D/HHS	690-5874	205-8838
Ken Bernard	NSC	456-9298	

MSPB

State

P3(b)(3)

12 March 1999

MEMORANDUM FOR:

John P. ...
Chief of Staff to the President

FROM:

Director of Central Intelligence

SUBJECT:

Proposed Executive Order to Prohibit
Discrimination in the Federal Employment
Based on Protected Genetic Information

I am writing to convey my substantive and procedural concerns on a draft Executive Order to "Prohibit Discrimination in Federal Employment Based on Protected Genetic Information." I am forced to bring our concerns to your attention at the eleventh hour because at a meeting earlier this week at the Old Executive Office Building, my staff was informed that the President was scheduled to sign the Order on Monday, 15 March, leaving us almost no time to work this issue in the ordinary way. Obviously, it would have been preferable had we been invited to participate in this initiative at a much earlier stage.

I understand that the draft Order is part of a White House initiative that has been in the works for two years, and that an interagency group participated in the drafting of this Order. Unfortunately, CIA was not made aware of the interagency group, and was not invited to play any role in the drafting of the order despite the fact that it would have a significant and adverse impact on our medical clearance procedures—including those applicable to overseas assignments.

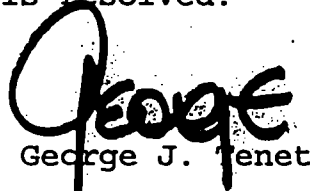
Overall, I agree with the thrust of the draft Order. Genetic information as such should not be used to make employment decisions. However, the draft Order would cover far more than that, due to the very broad definition of the term "protected genetic information." Because it includes the phrase "information about the occurrence of a disease or disorder in family members of the individual," the draft Executive Order's restrictions would cover not only information derived from genetic tests, but even the routine consensual collection and use of information about the subject's family medical history. Such information is, as you know, one of the many data a medical professional may find helpful in making a correct diagnostic decision. Denying our medical staff access to such information could needlessly jeopardize the health of our employees, particularly those who may, in the course of their duties,

SUBJECT: Proposed Executive Order to Prohibit
Discrimination in the Federal Employment
Based on Protected Genetic Information

find it necessary to travel abroad in areas where western
medical standards are unknown.

I believe our concerns regarding the draft Order can be
accommodated by adding specific language to permit the
collection and use of data concerning family medical history
for certain limited purposes. I am attaching a copy of our
proposed revision, which we have also provided to OMB.

I appreciate your giving this matter careful
consideration, reiterate our support for the overall
objectives of the proposed Executive Order, and ask that you
keep me informed—either directly or through my General
Counsel—as this matter is resolved.


George J. Tenet

Attachment:
as stated

 Bob. We need to make Ophiob because
HIO really important to us.
Bob McNamee y prepared
to help



1-403. An agency head may:

(a) determine that the collection of protected genetic information is required from an individual, after a conditional offer of employment is made, or in the course of employment, when the collection of such protected genetic information is job-related and consistent with applicable law; and

(b) determine that the use of such protected genetic information is necessary in connection with making an employment or overseas assignment decision consistent with the applicable law.

EXECUTIVE ORDER

TO PROHIBIT DISCRIMINATION IN FEDERAL EMPLOYMENT BASED ON PREDICTIVE GENETIC INFORMATION

By virtue of the authority vested in me as President of the United States by the Constitution and statutes of the United States, it is ordered as follows:

Nondiscrimination in Federal Employment on the Basis of Predictive Genetic Information

1-101. It is the policy of the Government of the United States to provide equal employment opportunity in Federal employment for all qualified persons and to prohibit discrimination against employees based on predictive genetic information or information about a request for or the receipt of genetic services. This policy of equal opportunity applies to every aspect of Federal employment.

1-102. The head of each Executive department and agency shall extend its program of equal employment opportunity to include the policy set forth in Section 1-101 for all its employees covered by Section 717 of Title VII of the Civil Rights Act of 1964 as amended.

Powers and Duties of the Equal Employment Opportunity Commission

1-201. The Equal Employment Opportunity Commission shall be responsible for directing and furthering the implementation of the policy of the Government of the United States to prohibit discrimination against employees in Federal employment based on predictive genetic information or information about a request for or the receipt of genetic services.

1-202. The Equal Employment Opportunity Commission is authorized to consult with all affected departments and agencies, to request from any affected department or agency such information as the Commission deems necessary and appropriate to carry out this Order, and to issue appropriate rules, regulations (including regulations that permit exemptions in addition to those set forth in Section 1-401), orders, and instructions. All affected departments and agencies

shall furnish to the Commission such information and assistance as the Commission may require in the performance of its functions under this Order and shall comply with any rules, regulations, orders, and instructions issued by the Commission.

Requirements Applicable to Employing Departments and Agencies

1-301. Definitions.

- (a) Commission means the Equal Employment Opportunity Commission or any person, department or agency to whom the Commission delegates responsibility under this Order.
- (b) The term "employee" shall include an employee, applicant for employment or former employee covered by Section 717 of the Civil Rights Act of 1964 (42 U.S.C. 2000e-16).
- (c) Genetic monitoring means the periodic examination of employees to evaluate acquired modifications to their genetic material, such as chromosomal damage or evidence of increased occurrence of mutations, that may have developed in the course of employment due to exposure to toxic substances in the workplace, in order to identify, evaluate, and respond to the effects of or control adverse environmental exposures in the workplace.
- (d) Genetic services means health services, including genetic tests, provided to obtain, assess, or interpret genetic information for diagnostic and therapeutic purposes, and for genetic education and counseling.
- (e) Genetic test means the analysis of human DNA, RNA, chromosomes, proteins, and certain metabolites in order to detect disease-related genotypes or mutations. Tests for metabolites are covered when an excess or deficiency of the metabolite indicates the presence of a mutation or mutations.
- (f) Predictive genetic information.
 - (1) In general, predictive genetic information means--
 - (A) information about an individual's genetic tests;

(B) information about genetic tests of family members of the individual; or

(C) information about the occurrence of a disease or disorder in family members of the individual.

- (2) Information about an individual's current health status (including information about sex, age, physical exams, and chemical, blood, or urine analyses of the individual) is not predictive genetic information unless it is described in subparagraph (1).

1-302. The Commission, in discharging its responsibilities under this order, shall implement the following nondiscrimination requirements.

- (a) The employing department or agency shall not discharge, fail or refuse to hire, or otherwise discriminate against any employee with respect to the compensation, terms, conditions, or privileges of employment of the employee, because of predictive genetic information with respect to the employee or because of information about a request for or the receipt of genetic services by such employee or by a family member of such employee.
- (b) The employing department or agency shall not limit, segregate, or classify employees in any way that would deprive or tend to deprive any employee of employment opportunities or otherwise adversely affect the employee's status, because of predictive genetic information with respect to the employee or because of information about a request for or the receipt of genetic services by such employee or by a family member of such employee.
- (c) The employing department or agency shall not request, require, collect or purchase predictive genetic information with respect to an employee or a family member of the employee or information about a request for or the receipt of genetic services by such employee or by a family member of such employee.
- (d) The employing department or agency shall not disclose predictive genetic information with respect to an employee or information about a request for or the

receipt of genetic services by an employee or by a family member of an employee except --

- (1) to the employee who is the subject of the information, at the request of that employee to whom disclosure is being made;
 - (2) to an occupational or other health researcher if the research is conducted in compliance with the regulations and protections provided for under part 46 of title 45, Code of Federal Regulations;
 - (3) under legal compulsion of a Federal court order, except that if the court order was secured without the knowledge of the individual to whom the information refers, the employer shall provide the individual with adequate notice to challenge the court order unless the court order also imposes confidentiality requirements; and
 - (4) to government officials investigating compliance with this Executive Order if the information is relevant to the investigation.
- (e) The employing department or agency shall not maintain predictive genetic information or information about a request for or the receipt of genetic services in general personnel files; such information shall be treated as confidential medical records, and kept separate from personnel files.

1-303. The remedies and procedures available under part 1614 of title 29, Code of Federal Regulations, to any individual or class of individuals alleging discrimination in violation of Title VII of the Civil Rights Act of 1964, the Age Discrimination in Employment Act, the Equal Pay Act, and the Rehabilitation Act of 1973 (29 U.S.C. 701 et seq.) shall be, within the limitations of applicable law, the remedies and procedures available to any individual or class of individuals alleging a violation of this Executive Order.

Exceptions

1-401. The following exceptions shall apply to the nondiscrimination requirements set forth in Section 1-302.

- (a) The employing department or agency may collect predictive genetic information with respect to an employee if:
 - (1) the employee or family member uses genetic or health care services provided by the employer;
 - (2) the employee or family member who uses the genetic or health care services has provided prior, knowing, voluntary, and written authorization to the employer to collect predictive genetic information;
 - (3) the person who performs the genetic or health care services does not disclose the results of the genetic services to anyone except the employee who uses the services; and
 - (4) such information is not used in violation of Sections 1-302(a) or 1-302(b) of this Executive Order.
- (b) Genetic monitoring of biological effects of toxic substances in the workplace shall be permitted if all of the following conditions are met:
 - (1) the employee has provided prior, knowing, voluntary, and written authorization;
 - (2) the employee is informed of the specific results of the monitoring;
 - (3) the employee is informed of any other predictive genetic information that may have been acquired, provided that the employee has given prior, knowing, voluntary, and written consent to such additional disclosure;
 - (4) the monitoring conforms to any regulations that may be promulgated by the Secretary of Labor; and
 - (5) the employer, excluding any licensed health care professionals that are involved in the genetic monitoring program, receives results of the monitoring only in aggregate terms that do not disclose the identity of specific employees.

- (c) This Executive Order does not limit the statutory authority of a Federal agency to
- (1) promulgate or enforce workplace safety and health laws and regulations or
 - (2) conduct or sponsor occupational or other health research that is conducted in compliance with regulations at part 46 of title 45, Code of Federal Regulations.

Miscellaneous

1-501. The Commission may delegate to any officer, agency, or employee in the Executive branch of Government, any function or duty assigned to it under this Order, except the authority to promulgate rules and regulations of a general nature.

1-502. The head of each department and agency shall take appropriate action to disseminate this policy, and to this end shall designate a high level official responsible for carrying out its responsibilities under this Executive Order.

1-503. Nothing in this Executive Order shall be construed to:

(a) limit the rights or protections of an individual under the Rehabilitation Act of 1973 (29 U.S.C. 701 et seq.) or the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.), including coverage afforded to individuals under section 102 of Americans with Disabilities Act of 1990;

(b) limit the rights or protections of an individual under any other Federal statute that provides equal or greater protection to an individual than the rights accorded under this Executive Order; or

(c) supersede any provision of the Privacy Act of 1974 (5 U.S.C. 552a), and actions taken under this Executive Order shall be in compliance with the Privacy Act.

THE WHITE HOUSE

DEPARTMENT OF HEALTH AND HUMAN SERVICES
ASSISTANT SECRETARY FOR PLANNING AND EVALUATION
OFFICE OF HEALTH POLICY



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