

NLWJC - Kagan

DPC - Box 028 - Folder 019

Health - Genetic Screening

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,

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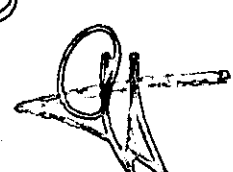
find it necessary to travel abroad in areas where western
medical standards are unknown.

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

*John. We need to make Ophiob because
it is really important to us.
Bob Mc Namara y prepared
to help*


PREVENTING INSURANCE DISCRIMINATION BASED ON GENETIC INFORMATION

Today the President pledged his commitment to enacting bipartisan legislation in this Congress to prohibit health plans from inappropriately using genetic screening information to deny coverage or set premiums, or distributing confidential information. In so doing, he released a new report from the Department of Health and Human Services that summarizes the promise and perils of genetic screening. He also announced that the Republican Chair of the Senate Labor and Human Resources Committee, Senator Jim Jeffords, and the Public Health and Safety Subcommittee Chair, Senator and Doctor Bill Frist, have indicated their support for passing a bipartisan bill that is consistent with the goals and general recommendations of the HHS report.

The Progress and Promise of Genetic Testing. Genetic testing has the potential to identify hidden genetic disorders and spur early treatment. Tests for genetic predisposition to certain diseases and conditions -- such as Huntington's disease and certain types of breast cancer -- are already available and more genetic tests are on the horizon.

Genetic Discrimination: The Perils of This Progress. But genetic testing also can be used by insurance companies and others to discriminate and stigmatize groups of people. Studies have shown that:

- Over one-fifth of people in families where someone has a genetic disorder report that they, or a member of their family, had been discriminated against by an insurance plan.
- 85 percent of Americans report that they are extremely concerned with the possibility that their genetic makeup will be used to discriminate against them or a member of their family.

Building on Kassebaum-Kennedy. Kassebaum-Kennedy took steps to prohibit genetic discrimination by preventing insurers from using genetic information as a "pre-existing condition" and denying or limiting coverage in group markets. However, Kassebaum-Kennedy falls short in three areas. It does not: (1) prevent health plans in the individual market from denying coverage on the basis of genetic information; (2) assure that premiums settings are in no way based on genetic information both in the group and individual market; and (3) prevent health plans from disclosing genetic information to insurers, to plan sponsors, and other entities regulated by state insurance laws, such as life, disability, and long-term care insurers.

State laws are insufficient. Nineteen states have already enacted laws to restrict the use of genetic information in health insurance and many others have introduced legislation. However, state legislation is insufficient to solve this problem. First, private sector employer sponsored health plans, which cover half of all Americans, are exempt from state insurance laws due to ERISA preemption. Second, current state laws generally focus on genetic tests rather than a broader definition of genetic information such as family history, medical records, and physical exams. Finally, the variability among state bills will lead to a lack of uniformity across the nation as to whether and how genetic information may be used by health plans.

Building on the existing bipartisan commitment to the President's challenge. Several bills have been introduced in this Congress which prohibit health plans from requesting or using genetic information to deny health care coverage or raise premiums. The bipartisan legislation introduced by Rep. Louise Slaughter, H.R. 306, addresses the three major gaps left by the HIPAA legislation and represents a strong foundation for this much-needed reform. It has already attracted over 150 cosponsors. The HHS report released today recommends building on this legislation and enacting a bill that protects all Americans from the threat of genetic discrimination.

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POTENTIAL GENETIC SCREENING EVENTS

Event with The Genome Action Plan. The Genome Action Plan, which consists of nearly one hundred groups -- including AARP, National Organization of Rare Disorders, National Alliance for the Mentally Ill, Parkinson's Disease Foundation, and the Cystic Fibrosis Foundation, and the March of Dimes -- is willing to design an event with us in order to highlight our report and support legislation on genetic discrimination. They are proposing an event that would take place at the National Academy of Sciences, which would include remarks by a few of their members and a couple of victims of genetic discrimination and the President or Vice President. NAS holds about 600 people. If we want a specific event for this, they are willing to design it as a legislative conference -- which would be appropriate since they too are about ready to announce their support of the Slaughter legislation. ✓ Report

Event in conjunction with announcement on new gene discovery. Apparently, there is a new gene discovery on a well-known late adulthood disease that is potentially being announced in the next month in *Science* magazine. *Science* has not decided when they will publish this gene, although there is fairly good chance they will publish it in late June or early July. They will be able to notify us between two and three weeks before publication. When they do publish, the Human Genome Institute plans to do a press conference on the discovery. This event -- could highlight the discovery and then emphasize that as we make these new breakthroughs on genetics, we should enact legislation to ensure that this genetic information is not used to discriminate against people. (Even if we do not want to use this to highlight the genetic screening legislation, we may want to consider some possible POTUS involvement). This event is not necessarily mutually exclusive from the event with the Genome Action Plan.

Event with the Society of the Advancement of Women's Research. This group is holding their annual awards event on June 24th, where they will give awards in the areas such as basic research, clinical research, and public policy. We could issue our report and announce our support for genetic screening legislation at that event. This event would obviously emphasize women's concerns about genetic screening in breast cancer.