NLWJC - Kagan

DPC - Box 028 - Folder 019

Health - Genetic Screening

Health- genetic discrimination

12 March 1999

MEMORANDUM FOR: John Podesta
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

George J. Tenet

Attachment:
as stated

Jan. We need some help here because it is really important to us. Bob McNamara is prepared to help

G

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.

Health-genetic screening

The Honorable Newt Gingrich
Speaker of the House
of Representatives
Washington, D.C. 20515

Dear Mr. Speaker:

Enclosed for the consideration of the Congress is a draft bill entitled the "Genetic Information Nondiscrimination in Health Insurance Act of 1997". The draft bill implements the recommendations made in the Secretary's Report to the President, "Health Insurance in the Age of Genetics", released on July 14, 1997.

The bill makes amendments to the Employee Retirement Income Security Act of 1974 (ERISA), the Public Health Service Act, and the Internal Revenue Code of 1986 to expand the prohibitions against discrimination based on genetic information enacted in the Health Insurance Portability and Accountability Act of 1996 (HIPAA). Key features of the bill are outlined below. The provisions of the bill are described in greater detail in the enclosed section-by-section summary.

The bill extends protection to group health plan and health insurance policy applicants and participants in several important ways. First, it expands the protections in the group market by prohibiting group market insurers or plans from requesting genetic information concerning an individual or disclosing an individual's genetic information to other insurers, plan sponsors, or entities that collect or disseminate insurance information. Limited exceptions are provided where the information is needed for claims payment, coordination of benefits, or medical diagnosis or treatment, or where an individual provides prior written authorization of a disclosure. The bill also clarifies that the HIPAA provisions prohibiting plans or insurers from denying or limiting coverage based on genetic information include an individual's request for, or receipt of, genetic services.

Second, the bill extends most group market genetic information restrictions to the individual market. An exception would permit insurers in the individual market to request medical information about a condition for which an individual had been previously diagnosed. These insurers are prohibited from requesting an individual to undergo a genetic test or using genetic information unrelated to a previously diagnosed condition to deny or limit coverage.

Finally, the bill expands HIPAA's premium related non-discrimination provisions. Under HIPAA, genetic information generally cannot be used to vary the premium rates of an individual in a group health plan. This bill explicitly prohibits the plan or insurer from varying the rate charged to the group based on genetic information pertaining to one or more of the group members.

The bill includes a variety of mechanisms to enforce these genetic information provisions. Individuals harmed by violations may sue for capped damages; the Secretary of Health and Human Services (HHS) may impose civil penalties for violations; and the Secretaries of Labor and HHS are authorized to order plans and insurers to issue or renew coverage which has been denied in violation of the bill's safeguards.

We urge the Congress to give the draft bill its prompt and favorable consideration.

The Office of Management and Budget has advised that there is no objection to the submission of this legislative proposal to the Congress, and that its enactment would be in accord with the program of the President.

Sincerely,

Donna E. Shalala

Enclosures

Health - genetic screening

MEMORANDUM

July 14, 1997

TO: Bruce Reed, Elena Kagan

FR: Chris J. and Sarah B.

RE: Documents for the Genetic Discrimination Event

Attached are the documents we put together for today's genetic information event. They include:

(1) One page fact sheet;

(2) An Executive Summary of the HHS report "Health Insurance in the Age of Genetics";

(3) One page summary of the legislation;

(4) Q&As;

(5) An impressive list of quotes from supportive Members and organizations;

(6) Today's *Post Story*.

We hope you find this information helpful. Please call with any questions.

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, set premiums, or to distribute 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 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 -- such as Huntington's disease and certain types of breast cancer -- are already available and more such tests are on the horizon.

Genetic Discrimination: The Perils of This Progress. 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. The Kassebaum-Kennedy law 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, it does <u>not</u>: (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; 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. Although 19 states have already enacted laws to restrict the use of genetic information in health insurance, state laws are insufficient to solve this problem. First, employer sponsored self-insured 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.

Building on the existing bipartisan commitment to the President's challenge. Bipartisan legislation introduced by Rep. Louise Slaughter (H.R. 306) and Senator Snowe (S. 422) 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 130 cosponsors in the House. The legislation that the President will be forwarding to the Hill builds off the Slaughter/Snowe bill and strengthens it by explicitly specifying that genetic information cannot be disclosed to insurers, plan sponsors (the employer), and other entities regulated by state insurance laws, such as life, disability, and long-term care insurers. It also gives the Secretary the authority to define others situations where it is appropriate to allow genetic information to be disclosed. This modification will ensure that genetic information can still be used, where appropriate, to help improve important biomedical research efforts.

HEALTH INSURANCE IN THE AGE OF GENETICS
AN EXECUTIVE SUMMARY

The "Health Insurance in the Age of Genetics" report responds to the President's request for information on the potentials and perils of genetic testing. It includes information on the current state of legislation about genetics as well as recommendations for Federal legislation to improve protections against genetic discrimination.

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. In the next few years we will know the location of nearly every human gene and we are learning more and more about how genes interact. As genetic information becomes increasingly common, it will revolutionize our health care system. With this new technology, Americans will be able to determine conclusively whether or not they are in fact genetically predisposed to a disease. Those who are can begin early and often life-saving treatment and those who are not will gain much-needed peace of mind.

Genetic Discrimination: The Perils of This Progress. While progress in genetics can help millions of Americans, we know that genetic testing can be used by insurance companies and others to discriminate and stigmatize groups of people. Even those who have not yet or may never show signs of a disease are still at risk for discrimination. Studies have shown that eighty-five percent of Americans are still extremely concerned with the possibility that their genetic makeup will be used to discriminate against them or a member of their family. Twenty-two percent of people in families where someone has a genetic disorder report that they have been discriminated against by an insurance plan. In genetic testing studies at the National Institutes of Health (NIH), nearly a third of eligible people offered a test for breast cancer refused to take it. The overwhelming majority of those who refused tests cite concerns about health insurance discrimination and loss of privacy as the reason why.

State Initiatives and Why These 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 for a number of reasons. First, private sector employer sponsored health plans, which covers 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.

HIPAA: Gaps in the Current Federal Legislation. HIPAA 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, HIPAA falls short in three areas. It does not: (1) prevent insurers in the individual market from denying coverage on the basis of genetic information; (2) assure that premiums are in no way based on genetic information both in the group and individual market; and (3) prevent insurance companies from disclosing genetic information to other insurers, to plan sponsors, and other entities regulated by state insurance laws, such as life, disability, and long-term care insurers.

Recommendations for Federal Legislation. Any Federal legislation should address the three major areas not included in HIPAA:

> **Access in the individual market.** The HIPAA protections should be extended to the individual market in the absence of a diagnosis. Only then will all Americans rest assured that they or their families will not be denied or lose their health care coverage based on their genetic information.
>
> **Affordability in the individual and group market.** HIPAA did not prevent insurers -- in either the individual or the group market -- from increasing group premium rates based solely on knowledge about genetic information. New legislation must ensure that health plans do not use genetic information in any way when determining premiums.
>
> **Disclosing Genetic Information.** New legislation should protect the privacy and confidentiality of genetic information by preventing health plans from releasing or demanding access to genetic information. It should impose restrictions on the disclosure of genetic information to other insurers, to plan sponsors, and other entities regulated by state insurance laws, such as life, disability, and long-term care insurers.

Congressional Initiatives. Several bills have been introduced in this Congress which prohibits 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. The report recommends that the Administration build on this legislation and enact a bill that protects all Americans from the threat of genetic discrimination.

Summary of the President's Genetic Anti-Discrimination Legislative Priorities

- **Assuring access in the individual market.** Assures that Americans who are insured through the individual market will not be denied or lose their health care coverage based on their genetic information.

- **Enhancing affordability in the individual and group market.** Prevents insurers -- in either the individual or the group market -- from increasing group premium rates based on knowledge about genetic information. New legislation must ensure that health plans do not use genetic information in any way when determining premiums.

- **Protecting against inappropriate disclosure of genetic information.**

  -- Protects the privacy and confidentiality of genetic information by preventing health plans from releasing or demanding access to genetic information.

  -- Specifically imposes restrictions on the disclosure of genetic information to other insurers, to plan sponsors, and other entities regulated by state insurance laws, such as life, disability, and long-term care insurers.

  -- Gives the Secretary additional authority to determine other situations where it is inappropriate for health plans to disclose genetic information.

  -- Protects biomedical research efforts by specifying which entities cannot receive genetic information from health plans. In so doing, it provides safe harbors for situations in which it is appropriate and, in fact, often extremely beneficial to disclose genetic information, including for important biomedical research efforts.

- **Providing for other technical modifications.** Contains other important technical changes to ensure that any legislation from the Hill does not undermine the Kassebaum-Kennedy legislation, does not interfere with the doctor-patient relationship, and does not impose undue administrative hassles on health plans.

QUESTIONS AND ANSWERS
ON PREVENTING GENETIC DISCRIMINATION
IN HEALTH INSURANCE

Q: IS THERE ANY EVIDENCE THAT INSURANCE COMPANIES ARE DISCRIMINATING AGAINST PEOPLE WITH A GENETIC PREDISPOSITION TO A DISEASE?

A: Medical researchers and physicians have reported that people are refusing to get genetic testing or to participate in medical research because they fear that this information could be used against them or a member of their family. We know that genetic information has been used to discriminate against people in the past.

In the early 1970's, health insurance coverage and jobs were denied to many African-Americans who were identified as carriers of sickle-cell anemia. We also know that a leading reason women refuse genetic testing for breast cancer is because they fear that insurance companies may charge excessively high premiums or deny health care coverage to either themselves or members of their families.

Moreover, over one-fifth of people who live in families where someone has a genetic disorder report that they have been discriminated against by an insurance plan. (Lapham et al., Science, October, 1996).

A 1985 Harris Poll of the general public revealed that over 85 percent of those surveyed indicated they were very concerned or somewhat concerned that insurers or employers might have access to and use genetic information.

Q: HOW MUCH WOULD THIS LEGISLATION COST?

A: We do not have any formal estimates on how much this legislation would cost. However, states that have enacted legislation in this area have not experienced any significant costs associated with it.

Q: HOW MANY AMERICANS WOULD BE AFFECTED BY THIS LEGISLATION?

A: This legislation would protect all Americans from having to pay higher premiums based on genetic information and from having their genetic information disclosed.

Q: WHY ISN'T THE ADMINISTRATION ADDRESSING THE PROBLEM OF EMPLOYMENT DISCRIMINATION BASED ON GENETIC SCREENING INFORMATION WITH THE SAME RIGOR IT IS TAKING IN THE HEALTH INSURANCE ISSUE?

A: Genetic discrimination by employers is no less an important issue. The Department of Labor, in conjunction with the Equal Employment Opportunity Commission, the Department of Justice, and the Department of Health and Human Services, is currently considering the feasiblity of extending protections beyond current law for this explicit purpose. We anticipate that we will have their findings and recommendations sometime later this year. As we review this issue, we look forward to working with Members of Congress -- such as Senator Tom Daschle -- who have shown an interest in this area.

Q: DIDN'T THE KASSEBAUM-KENNEDY HEALTH REFORM LEGISLATION TAKE CARE OF THIS PROBLEM?

A: The Kassebaum-Kennedy legislation did take important steps to prevent health insurers from discriminating on the basis of genetic information. However, this legislation builds on these provisions in three important areas. It: (1) prevents insurers in the individual market from discriminating on the basis of genetic information in the absence of a positive diagnosis or treatment; (2) assures that group premiums, both in the group and the individual market, are not based on genetic information; and (3) restricts insurers and health plans from disclosing genetic information.

Access in the individual market. The HIPAA protections should be extended to the individual market. Only then will all Americans rest assured that they or their families will not be denied or lose their health care coverage based on their genetic information.

Affordability in the individual and group market. The Kassebaum-Kennedy legislation did not prevent insurers -- in either the individual or the group market -- from increasing group premium rates based on knowledge about genetic information. New legislation must ensure that health plans do not use genetic information in any way when determining premiums.

Disclosing Genetic Information. New legislation should protect the privacy and confidentiality of genetic information by preventing health plans from releasing or demanding access to genetic information. It should impose restrictions on the disclosure of genetic information to other insurers, to plan sponsors, and other entities regulated by state insurance laws, such as life, disability, and long-term care insurers.

Q: THERE ARE A NUMBER OF BILLS ON THE HILL ON THIS ISSUE. WHY DOES THE PRESIDENT LIKE THE ONE INTRODUCED BY REPRESENTATIVE SLAUGHTER AND SENATOR SNOWE?

A: While there are many bills on the Hill and many important legislators with commendable commitments in this area, the President believes that this is the strongest bill to build on. The bill is based on the joint recommendations made by the National Institutes of Health's Working Group on Ethical, Legal, Social Implications of Human Genome Research (ELSI Working Group) and the National Action Plan on Breast Cancer (NAPBC) to address the issue of genetic discrimination and health insurance. It addresses the three major gaps left by Kassebaum-Kennedy: (1) preventing health plans in the individual market from denying coverage on the basis of genetic information; (2) assuring that premiums settings are in no way based on genetic information; and (3) preventing 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.

Q: WHAT ARE THE DIFFERENCES BETWEEN THE SLAUGHTER-SNOWE LEGISLATION AND THE LEGISLATION THAT PRESIDENT IS SENDING TO CONGRESS?

A: The legislation that the President will be forwarding to the Hill builds off the Slaughter/Snowe bill and strengthens it by explicitly specifying that genetic information cannot be disclosed to insurers, plan sponsors (the employer), and other entities regulated by state insurance laws, such as life, disability, and long-term care insurers. It also gives the Secretary the authority to define other situations where it is appropriate to allow genetic information to be disclosed. This modification will ensure that genetic information can still be used, where appropriate, to help improve important biomedical research efforts. It also prohibits insurers from varying premiums in a group plan based on the genetic information of any individual in that group. It also contains some technical changes that protects the intent of the Kassebaum-Kassebaum and ensures that the patient-doctor relationship is not undermined.

Q: REPRESENTATIVES OF SOME DRUG COMPANIES SUCH AS THE PHARMACEUTICAL RESEARCH AND MANUFACTURERS ASSOCIATIONS (PhRMA) THAT DO BIOMEDICAL RESEARCH ARE CONCERNED THAT THIS LEGISLATION WOULD PREVENT RESEARCHERS FROM GETTING ACCESS TO MUCH-NEEDED GENETIC INFORMATION. WILL THIS LEGISLATION UNDERMINE OUR PROGRESS IN THIS AREA?

A: Absolutely not. We want to make sure that this legislation does not undermine these important research efforts. In fact, part of the reason why the President is forwarding legislation to the Hill to improve on the Slaughter-Snowe legislation is that he wants to make sure that we have clarified the underlying bill to ensure that efforts bolster -- not harm -- the efforts of biomedical researchers.

Researchers like Dr. Francis Collins of the National Institute of Health's Human Genome Project are some of the strongest supporters of the President's efforts. Fear of genetic discrimination by potential research subjects has been cited as the biggest impediment to research in these fields. By removing this fear, the Administration will greatly reduce the number of potential research participants who presently shy away from participating in studies.

Q: AREN'T MANY STATES TAKING ACTION ON THIS ISSUE? WHY DO WE NEED FEDERAL LEGISLATION?

A: While nineteen states have taken action in this area and many more have proposed legislation this year, state legislation is insufficient to solve this problem. The variability among state bills could lead to a lack of uniformity across the nation as to whether and how genetic information may be used by health plans. Moreover, the Employer Retirement Income Security Act (ERISA) exempts private sector employer-sponsored health plans that provide benefits through self-funded arrangements from state insurance laws. Thus, even if states enact legislation restricting the use of genetic information nearly one-half of the American population, would not protected.

For the most part, health insurance plans do not have formal guidelines about coverage of genetic tests, instead making decisions to cover based on individual considerations. A Task Force on Genetic Testing survey of HMOs found that some, but not most, do cover predictive testing for breast and colon cancer in asymptomatic people. Kaiser Permanente and Blue Cross/Blue Shield have conducted in-House technology assessments of the BRCA1/2 tests and both have formulated policies for covering BRCA1/2 testing under certain conditions.

Q: WON'T THE GENETIC SCREENING ISSUE BE ADDRESSED BY THE HHS SECRETARY WHEN SHE RELEASES HER STATUTORILY REQUIRED REPORT ON PRIVACY ISSUES LATER THIS YEAR? ISN'T THE WORK BY MEMBERS INTERESTED IN PRIVACY, DISCLOSURE AND CONFIDENTIALITY ISSUES GOING TO ADDRESS THIS PROBLEM?

A: Scientific experts from the NIH feel strongly that the genetic information challenge raises a host of issues that merit immediate and separate attention. While there may be some overlap on these efforts, we believe this to best way to most comprehensively and effectively address this issue.

The patient confidentiality issues that HHS and the Congress are looking at separate and apart from the genetic information issue relate generally to diseases that individuals already have. In contrast, predilection and susceptibility to disease may raise different issues. Moreover, genetic information not only applies to one's own medical history, but to those of future generations as well.

These are all complicated and very unique matters that require very careful and deliberate consideration. They also merit separate legislation at least at the beginning of the legislative process.

Statements of Support for the President's Action on Genetic Discrimination

"I am very pleased to express my commitment to working with President Clinton and my colleagues in the Senate to develop bipartisan legislation designed to protect each and every one of us from being unfairly discriminated against on the basis of our genetic make-up."

-- Senator Jim Jeffords,
Chair, Senate Labor and
Human Resources Committee

"In my role as chairman of the Subcommittee on Public Health and Safety, I strongly support the intent of legislation which would prohibit discrimination in health insurance against healthy individuals and their families based on genetic information."

-- Senator Bill Frist
Chair, Subcommittee on Public
Health and Safety, Labor and Human
Resources Committee

"We owe a debt of gratitude to President Clinton, Vice President Gore, Secretary Shalala, and Dr. Collins for their hard work and leadership on bringing this issue to the public's attention, and I am so pleased that the Administration has pledged to fight for passage of this important legislation."

-- Representative Louise Slaughter

"On behalf of more than 400 organizations and 51,000 individuals who are members of the National Breast Cancer Coalition, I want to thank you for your leadership in support of legislation to protect women and their families from insurance discrimination on the basis of predisposition to disease.

As we have said many times in the past, you have shown time and again that you have the vision and the courage to take on the tough issues in breast cancer, to do the right thing rather than espouse the simple or popular position."

-- National Breast Cancer Coalition

"The Women's Legal Defense Fund applauds you for taking the lead on yet another issue of tremendous importance to women and their families -- prohibiting genetic discrimination in health insurance."

-- Women's Legal Defense Fund

"The Hereditary Susceptibility Working Group of the National Action Plan on Breast Cancer applauds your leadership and support of legislation to prohibit health insurance discrimination based on genetic information. We are very gratified that your personal commitment will bring this issue to the attention of the American public. While women can survive breast cancer, they cannot survive without health insurance."

-- National Action Plan on Breast Cancer

"The issue of genetic nondiscrimination is not just about Jewish women, or even about breast cancer. As scientists race to map the human genome, this issue is sure to affect everyone. [...] Hadassah strongly applauds your endorsement of this historic legislation."

-- Hadassah,
The Women's Zionist
Movement of America

"We are deeply grateful to you for championing this important issue."

--Virginia Breast Cancer Foundation

"The Genome Action Coalition, comprised of more than 115 organizations, foundations, and corporations, would like to congratulate you and thank you for the extraordinary leadership you have shown with regard to the difficult issues which come about as a result of the progress of the Human Genome Project."

-- The Genome Action Coalition

"On behalf of the trustees and scientists of the Hereditary Disease Foundation, I wish to express our deep appreciation for your support of policies to prevent health insurance discrimination based on genetic information."

-- Hereditary Disease Foundation

"Your support [...] would help provide the protection against the misuse of genetic information that causes our families with genetic disorders to continue to be so vulnerable."

-- Alliance of Genetic Support Groups

"As the parent of a young adult with an incurable genetic disorder and as the past president of The Alliance of Genetic Support Groups, I am writing to thank you for speaking out against genetic discrimination."

-- Jayne Mackta,
Past President,
Alliance of Genetic Support Groups

"It is so important that you, as the leader of our fine nation, support this legislation so that an individual can not be discriminated against because they have a disease like Tuberous Sclerosis Complex, cystic fibrosis, Huntington's Disease, or any one of the genetic disorders."

-- National Tuberous Sclerosis Association

"This is an especially important issue for those at risk for Huntington's Disease, who often must live in fear not only of having an inherited disease, but also of losing their jobs and their health benefits when they are in need of them most."

-- Huntington's Disease Society of America

"We are thrilled with your support of legislation preventing genetic discrimination in health insurance. [...] We feel it is obscene for insurance companies to deny coverage to people like us merely because science has now provided a way to know about our genetic defects."

-- A-T Children's Project

"Your support of this legislation to prohibit genetic discrimination is very much needed to give the proposal the necessary momentum to gather votes and pass Congress. We need the protection this legislation can provide and appreciate all the help you can bring to resolve this problem."

-- Sickle Cell Service

"I am writing to applaud your announcement of support for legislation which would protect consumers from health insurance discrimination on the basis of genetic information. [...] These safeguards are crucial to keep scientific advances from becoming cruelly misused in our society."

-- American Nurses Association

"The American Academy of Pediatrics applauds your action on the issue of genetic screening. Your dedicated leadership on this issue is critical to protecting those children vulnerable to genetic discrimination."

-- American Academy of Pediatrics

"The Center for Patient Advocacy strongly supports your efforts to protect American patients from genetic discrimination. [...] With your leadership and active support we are confident that the patients of today and those of tomorrow benefit from the medical technology that advances in genetics make possible. We, at the Center for Patient Advocacy, applaud your efforts in behalf of all American patients."

-- Center for Patient Advocacy

Clinton to Support Legislation Guarding Against Gene-Test Bias

Inherited Risk for Disease Has Kept Some From Getting Insurance

By Rick Weiss
Washington Post Staff Writer

President Clinton today will endorse legislation that would make it illegal for health insurance companies to discriminate against healthy people on the basis of their genetic inheritance and would help assure the privacy of genetic information, White House sources said.

Clinton's call for legislation with more protections against genetic discrimination than those included in last year's Kassebaum-Kennedy health law comes as rapid-fire biological discoveries are giving doctors and researchers increasing ability to predict who will succumb to various inherited diseases.

Already, widely available blood tests can reveal whether a person harbors aberrant genes that increase the risk of getting breast cancer, colon cancer, melanoma, or brain diseases such as Alzheimer's and Huntington's disease. Dozens of other predictive genetic tests are available through research studies and may make their way to the market in the next few years.

In some cases the information can motivate a person to get more frequent checkups or take preventive action. But genetic information is imprecise and can stigmatize healthy people. Public policy regarding its use has lagged behind the science.

Clinton's decision to push for heightened protections reflects recommendations in a report to be presented to the president today by Health and Human Services Secretary Donna E. Shalala. The report, based on findings of a federal task force, warns that the potential benefits of genetic testing may never be realized if people reject the tests out of fear that the information may be used against them.

A number of genetic discrimination cases have come to light in recent years, most of them involving people who were denied health insurance because of test results indicating they were at increased risk of cancer or other diseases. In some cases people have been discriminated against simply for having requested genetic tests, as insurers assumed that anyone asking for such a test was probably at increased risk for an inherited disease.

The legislation to be endorsed by Clinton is a slightly modified version of a bill introduced in January by Rep. Louise M. Slaughter (D-N.Y.) that already has bipartisan support with more than 135 co-sponsors. The president's decision to get involved could rejuvenate a Senate bill with language identical to the House version, introduced by Sen. Olympia J. Snowe (R-Maine).

"The president is well aware that people are both excited and nervous by all the recent changes rooted in the biological revolution, and he believes that [the legislation] will provide a security blanket," said Christopher Jennings, deputy assistant to the president for health policy development. "It tells Americans we are watching the health care system, and people are going to be protected."

The president's hopes of warming the Senate to his plan were bolstered over the weekend when Sen. Bill Frist (R-Tenn.) agreed to back the effort. Frist's support was considered crucial, administration sources said, because he is the Senate's sole physician and chairs the subcommittee on public health and safety.

The Slaughter legislation would prohibit health insurers from denying, canceling, refusing to renew or changing the terms, premiums or conditions of health coverage on the basis of genetic information. It also would prevent health insurers from demanding a genetic test as a condition of coverage and, with few exceptions, would require a patient's written consent before the insurer could disclose genetic information to a third party. Companies found in violation of these protections could be sued for compensation and also would be liable for punitive damages.

The Health Insurance Portability and Accountability Act passed last year prevents health insurers from denying insurance on the basis of genetic information to people moving from one group plan to another. But the measure, which was sponsored by Sens. Nancy Landon Kassebaum (R-Kan.) and Edward M. Kennedy (D-Mass.), places no controls on how expensive that coverage might get. The act also offers no protections for people covered by individual, rather than group, plans.

"The Slaughter legislation definitively closes the loopholes left by Kassebaum-Kennedy and would offer comprehensive protections against genetic discrimination in health insurance," said Wendy McGoodwin, executive director of the Council for Responsible Genetics, an advocacy group based in Cambridge, Mass.

Congressional and administration sources said they believe there is a good chance that the proposed legislation or something close to it can become law this year. Ongoing changes in the health care system and especially the growth of managed care have raised so many concerns in both parties, one source said, that there is wide support for almost any issue that falls under the umbrella of protecting patients.

Indeed, several geneticists said, a ban on genetic discrimination in health insurance is one of the easier gene issues facing Congress—stirring only modest dissent even from health insurers, which are already restricted by similar laws in dozens of states. More difficult issues include a comprehensive ban on genetic discrimination in employment, possible restrictions on the use of genetic tests in life insurance underwriting and stricter regulation of the genetic testing industry.

Neil A. Holtzman, director of genetics and public policy studies at Johns Hopkins University, warned against interpreting the president's words today as an endorsement of widespread genetic testing. Holtzman chairs a federal task force that recently completed a study of genetic testing in the United States. That study is soon to be forwarded to Shalala.

The task force concluded that many genetic tests are being developed and administered without proper oversight, are being performed in inadequately regulated laboratories and are interpreted by physicians and others with insufficient training or proof of competence.

Other experts have criticized the rapidly growing genetic testing industry for offering many tests that have no proven medical usefulness for patients.

"Certainly the biotech industry will support a bill like [Slaughter's] because it removes a barrier to testing," Holtzman said. "Does that mean that people should flock to these tests? I don't think so."

Nonetheless, Holtzman and others said, some genetic tests are clearly useful, but people will not benefit from them if they are too afraid to take them.

"Increasingly we are finding that people are worried about participating in genetic research or clinical testing because of the great concern—and justifiably so—that it might be used against them," a senior National Institutes of Health official said. "It hinders research and hinders people's ability to take advantage of preventive medical strategies. We can really celebrate the fact that the president is giving this issue this degree of visibility and personal commitment."

The Washington Post
Monday, July 14, 1997

Health - genetic screening

THE WHITE HOUSE

WASHINGTON

July 12, 1997

GENETIC SCREENING EVENT

DATE: July 14, 1997
TIME: 2:30 pm - 3:40 pm
LOCATION: The East Room
FROM: Bruce Reed
Maria Echaveste

I. PURPOSE:

(1) To pledge to enact bipartisan legislation to prohibit health plans from inappropriately using genetic screening information to deny coverage or set premiums, or distributing confidential information; (2) To receive a new report from HHS on the promise and perils of genetic screening; and (3) To announce 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 consistent with the goals and recommendations of the HHS Report.

II. BACKGROUND:

While progress in genetic testing has helped millions of Americans, genetic testing can be used by insurance companies and others to discriminate and stigmatize groups of people. Studies show that 22 percent of people in families where someone has a genetic disorder report that they, or a member of their family, have been discriminated against by an insurance plan. In addition, 85 percent of Americans are extremely concerned with the possibility that their genetic makeup will be used to discriminate against them or a member of their family.

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 for three reasons: (1) private sector employer sponsored health plans, which cover half of all Americans, are exempt from state insurance laws due to ERISA preemption; (2) 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; and (3) 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.

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 insurers 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 insurance companies from disclosing genetic information to other insurers, to plan sponsors, and other entities regulated by state insurance laws, such as life, disability, and long-term care insurers.

III. PARTICIPANTS:

Briefing Participants
Bruce Reed
Maria Echaveste
Chris Jennings
Jordan Tamagni

Event Participants
The Vice President
Secretary Shalala
Congresswoman Louise Slaughter
Mary Jo Ellis Kahn, breast cancer survivor.

> [Mary Jo's mother was diagnosed with breast cancer. She was the mother of 5 children and died at the age of 47. Her four daughters knew they were at increased risk of breast cancer because of their mother's history. Mary Jo was diagnosed with breast cancer at age 39 and her older sister was diagnosed at age 42. The two younger sisters then decided to undergo preventive mastectomies. Mary Jo believes that the option of seeking genetic testing to discover the breast cancer gene will only be real if there is no chance of insurance discrimination.]

Audience
The audience consists of Members of Congress and 150 representatives of organizations endorsing Congresswoman's Slaughter's legislation, including breast cancer and consumer groups. Members of the working groups of the Human Genome Research Institute and the National Action Plan on Breast Cancer will also be in attendance.

Pre-Event Meet and Greet
- Mary Jo Ellis Kahn and family.
- Dana Glover, a fellow Arkansan, who at the age of 28 developed third stage breast cancer as a result of a mutated gene. She wrote to the White House several times and received no response, but when you saw her letter you asked that she be invited to the White House for an event.

IV. SEQUENCE OF EVENTS:

- You will be announced onto the stage with other participants.
- The Vice President will make welcoming remarks and introduce Secretary Shalala.
- Secretary Shalala will make remarks and introduce Congresswoman Slaughter.
- Congresswoman Slaughter will make remarks and introduce Mary Jo Ellis Kahn.
- Mary Jo Ellis Kahn will make remarks and introduce you.
- You will make remarks and then depart.

V. PRESS COVERAGE:

Open

VI. REMARKS:

Prepared by Jordan Tamagni.

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.

FINAL

Health - genetic screening

PREVENTING INSURANCE DISCRIMINATION BASED ON GENETIC INFORMATION

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Health – genetic screening

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.

Health-genetic screening

POTENTIAL GENETIC SCREENING EVENT

We are proposing to do an event with The Genome Action Plan (TGAP), which consists of nearly one hundred groups -- including AARP, National Organization of Rare Disorders, National Alliance for the Mentally Ill, the American College of Gynecologists and Obstetricians, the Cystic Fibrosis Foundation, the March of Dimes and a number of women's groups.

This event would include a major women's component, as a top concern for many women is the potential for discrimination for those who have been identified as having the gene which predisposes one to breast cancer. The National Action Plan on Breast Cancer would play an active role in the event. We could also include the National Breast Cancer Coalition, and other women's groups. Also, auto-immune diseases, such as Multiple Sclerosis and lupus, that are often genetically based disproportionately impact women. For example, 75 percent of the population suffering from Multiple Sclerosis are women.

At this event, the NAPBC and The Genome Action Plan would announce their support for the legislation introduced by Louise Slaughter which the President indicated his support for at his Morgan State Commencement speech last month. The event would also highlight a new HHS report on the need for genetic legislation and reiterate our support legislation for the Slaughter legislation. (Slaughter would also play an active role in this event).

The Genome Action Plan is interested in holding this event at the National Academy of Sciences, which holds about 600 people. This would provide a nice follow-up to the emphasis on science in the President's Morgan State speech.

NIH believes that we could get lots of media attention on this issue. Dr. Francis Collins, the Director of the Human Genome Project at NIH is being interviewed for a *New York Times Magazine* story on genetic discrimination this Friday. If we could promise a Presidental or Vice Presidental event, the journalist has indicated that she may be willing to wait for the story. If this is the case, we are far more likely to get coverage which emphasizes the President's leadership on this issue. Otherwise the story will likely only mention the work by Dr. Collins as well as the numerous pieces of legislation on the Hill. NIH has also had preliminary discussions with ABC, CNN, and others.

Health - genetic screening

SCHEDULE REQUEST PROPOSAL

6/9/97

_______ ACCEPT _______ REGRET _______ PENDING

TO:
Stephanie Streett
Deputy Assistant to the President &
Director of Scheduling

FROM: Bruce Reed, Assistant to the President for Domestic Policy

REQUEST: Event with The Genome Action Plan to highlight our support of legislation prohibiting insurance companies from discriminating against people based on their genetic information.

PURPOSE: To highlight our support for legislation prohibiting insurers from using genetic screening information to discriminate or underwrite, to release a new HHS report on the potentials and perils of genetic information, to announce the news that women's groups and the National Genome Action Plan are supporting the President on this initiative and to emphasize the importance of this legislation to women's groups who are concerned about the potential for women who may be discriminated against because of genetic information, particularly women with breast cancer.

BACKGROUND: This event would be held at the National Academy of Sciences with the National Action Plan on Breast Cancer, the National Breast Cancer Coalition and The Genome Action Plan, a broad coalition consisting of over 100 groups, including AARP, the National Alliance for the Mentally Ill, Parkinson's Disease Foundation, the American College of Gynecologists and Obstetricians, and the March of Dimes

The event would highlight the potential and perils of new information from the Human Genome Project that enables us to identify potential genetic disorders. In particular, it would highlight the need for legislation to protect Americans from genetic discrimination.

PREVIOUS PARTICIPATION:	None
DATE AND TIME:	Late June
DURATION:	1 hour
LOCATION:	National Academy of Sciences
OUTLINE OF EVENTS:	Members from one or two of the groups involved in The Genome Action Plan speaks, including a breast cancer group; a victim of genetic discrimination; Dr. Collins, the director of the Human Genome Project; Rep. Louise Slaughter (the sponsor of the legislation we are supporting) and introduces the President; and the President delivers remarks and announces the release of the HHS genetic information report.
REMARKS REQUIRED:	Prepared by speech writing.
FIRST LADY'S ATTENDANCE:	Not required.
VICE PRESIDENT'S ATTENDANCE:	Not required.
SECOND LADY'S ATTENDANCE:	Not required.
RECOMMENDED BY:	Bruce Reed, Chris Jennings
CONTACT:	Chris Jennings, 456-5560
ORIGIN OF PROPOSAL:	Domestic Policy Council. To follow-up on the commitment to this issue that the President announced at Morgan State last month.

Addendum: The New York Times Magazine is doing a story on genetic screening in the next month or so. If we can give the journalist a date for an event fairly soon, the journalist will wait to run the story, and the President can get credit as a leader on this issue.

Health - genetic screening

Total Pages: ____

LRM ID: MDH75

EXECUTIVE OFFICE OF THE PRESIDENT
OFFICE OF MANAGEMENT AND BUDGET
Washington, D.C. 20503-0001

URGENT

Friday, May 30, 1997

LEGISLATIVE REFERRAL MEMORANDUM

TO: Legislative Liaison Officer - See Distribution below

Connie J Bowers for

FROM: Janet R. Forsgren (for) Assistant Director for Legislative Reference

OMB CONTACT: Robert J. Pellicci
PHONE: (202)395-4871 FAX: (202)395-6148

SUBJECT: HHS Draft Bill on Genetic Information Nondiscrimination in Health Insurance Act of 1997

DEADLINE: Noon Tuesday, June 3, 1997

In accordance with OMB Circular A-19, OMB requests the views of your agency on the above subject before advising on its relationship to the program of the President. Please advise us if this item will affect direct spending or receipts for purposes of the "Pay-As-You-Go" provisions of Title XIII of the Omnibus Budget Reconciliation Act of 1990.

COMMENTS: We understand that the Vice President may announce the attached HHS draft bill at an event scheduled for Saturday, June 7th. For this reason, this deadline is firm.

DISTRIBUTION LIST

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OMB-LA

A BILL

To prohibit discrimination against individuals and their family members on the basis of genetic information, or a request for genetic services.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the "Genetic Information Nondiscrimination in Health Insurance Act of 1997".

SEC. 2. AMENDMENTS TO EMPLOYEE RETIREMENT INCOME SECURITY ACT OF 1974.

(a) PROHIBITION OF HEALTH INSURANCE DISCRIMINATION ON THE BASIS OF REQUEST FOR OR RECEIPT OF GENETIC SERVICES.—

(1) NO ENROLLMENT RESTRICTION FOR GENETIC SERVICES.—Section 702(a)(1)(F) of the Employee Retirement Income Security Act of 1974 (29 U.S.C. 1182(a)(1)(F)) is amended by inserting before the period "or request for or receipt of genetic services".

(2) NO DISCRIMINATION IN GROUP RATE BASED ON GENETIC INFORMATION.—Section 702(b)(1) of such Act (29 U.S.C. 1182(b)(1)) is amended—

(A) by striking "may not require any individual" and inserting "may not—

(A) require any individual";

(B) by moving the remainder of the paragraph two ems to the right;

(C) by striking the period and adding "; or"; and

(D) by adding at the end the following new subparagraph:

"(B) adjust premium or contribution rates for a group or the individuals in a group on the basis of genetic information concerning or a request for or receipt of genetic services by any member of such group or a covered dependent of such member.".

(b) LIMITATION ON COLLECTION AND DISCLOSURE OF GENETIC INFORMATION.—Section 702 of such Act (29 U.S.C. 1182) is amended by adding after subsection (b) the following new subsection:

"(c) WITH RESPECT TO COLLECTION AND DISCLOSURE OF GENETIC INFORMATION.—

"(1) COLLECTION.—Except as provided in paragraph (3), a group health plan, or a health insurance issuer offering health insurance coverage in connection with a group health plan, shall not request or require disclosure of genetic information concerning an individual who is a participant or beneficiary (or an applicant for coverage as a participant or beneficiary).

"(2) DISCLOSURE.—Except as provided in paragraph (3)—

"(A) a group health plan, or a health insurance issuer offering health insurance coverage in connection with a group health plan, shall not disclose genetic information about an individual who is a participant or beneficiary (or an applicant for coverage as a participant or beneficiary) to any other health plan or health insurance issuer or to the plan sponsor or plan administrator; and

"(B) a physician, hospital, or other person that provides health care items or services to an individual shall not disclose genetic information about such individual to any group health plan, or health insurance issuer offering health insurance coverage in connection with a group health plan.

"(3) EXCEPTIONS.—

"(A) The provisions of paragraphs (1) and (2) shall not apply to a request by or disclosure to a health plan or issuer that provides reasonable assurances that it provides health insurance coverage to such individual and requires such information for payment of claims or coordination of benefits.

"(B) Notwithstanding paragraphs (1) and (2), a health plan or issuer that provides health care items and services and provides reasonable assurances that it requires such information for diagnosis or treatment of such individual may—

(i) request (but not require) disclosure of such information by the individual; and

(ii) request or require such information from another health plan, or health insurance issuer, or provider of health care items and services.

"(C) The provisions of paragraphs (1) and (2) shall not apply if the individual, or the individual's legal representative, provides prior written authorization of such disclosure.".

(c) DEFINITIONS. Section 706(d) of such Act (29 U.S.C. 1191b(d)) is amended by adding at the end the following new paragraphs:

"(5) FAMILY MEMBER.—The term 'family member' means, with respect to an individual, a spouse or adopted child of that individual, or another individual related by blood to that individual or to a spouse or adopted child of that individual.

"(6) GENETIC INFORMATION.—The term 'genetic information' means information about genes, gene products, or inherited characteristics that may derive from an individual or a family member.

"(7) GENETIC SERVICES.—The term 'genetic services' means health services provided to obtain, assess, and interpret genetic information for diagnostic and therapeutic purposes, and for genetic education and counselling.".

(d) EFFECTIVE DATE.—The amendments made by this section shall apply with respect to group health plans and group health insurance coverage for plan years beginning after 1 year after the date of the enactment of this Act.

SEC. 3. AMENDMENTS TO THE PUBLIC HEALTH SERVICE ACT.

(a) AMENDMENTS RELATING TO THE GROUP MARKET.—

(1) PROHIBITION OF HEALTH INSURANCE DISCRIMINATION ON THE BASIS OF REQUEST FOR OR RECEIPT OF GENETIC SERVICES.—

(A) NO ENROLLMENT RESTRICTION FOR GENETIC SERVICES.—Section 2702(a)(1)(F) of the Public Health Service Act (42 U.S.C. 300gg-1(a)(1)(F)) is amended by inserting before the period "or request for or receipt of genetic services".

(B) NO DISCRIMINATION IN GROUP RATE BASED ON GENETIC INFORMATION.—Section 2702(b)(1) of such Act (42 U.S.C. 300gg-1(b)(1)) is amended

(i) by striking "may not require any individual" and inserting "may not—

(A) require any individual";

(ii) by moving the remainder of the paragraph two ems to the right;

(iii) by striking the period and adding "; or"; and

(iv) by adding at the end the following new subparagraph:

"(B) adjust premium or contribution rates for a group or the individuals in a group on the basis of genetic information concerning or a request for or receipt of genetic services by any member of such group or a covered dependent of such member.".

(2) LIMITATION ON COLLECTION AND DISCLOSURE OF GENETIC INFORMATION.—Section 2702 of such Act (42 U.S.C. 300gg-1) is

amended by adding after subsection (b) the following new subsection:

"(c) WITH RESPECT TO COLLECTION AND DISCLOSURE OF GENETIC INFORMATION.

"(1) COLLECTION. Except as provided in paragraph (3), a group health plan, or a health insurance issuer offering health insurance coverage in connection with a group health plan, shall not request or require disclosure of genetic information concerning an individual who is a participant or beneficiary (or an applicant for coverage as a participant or beneficiary).

"(2) DISCLOSURE.—Except as provided in paragraph (3)—

"(A) a group health plan, or a health insurance issuer offering health insurance coverage in connection with a group health plan, shall not disclose genetic information about an individual who is a participant or beneficiary (or an applicant for coverage as a participant or beneficiary) to any other health plan or health insurance issuer or to the plan sponsor or plan administrator; and

"(B) a physician, hospital, or other person that provides health care items or services to an individual shall not disclose genetic information about such individual to any group health plan, or health insurance issuer offering health insurance coverage in connection with a group health plan.

"(3) EXCEPTIONS.—

"(A) The provisions of paragraphs (1) and (2) shall not apply to a request by or disclosure to a health plan or issuer that provides reasonable assurances that it provides health insurance coverage to such individual and requires such information for payment of claims or coordination of benefits.

"(B) Notwithstanding paragraphs (1) and (2), a health plan or issuer that provides health care items and services and provides reasonable assurances that it requires such information for diagnosis or treatment of such individual may—

(i) request (but not require) disclosure of such information by the individual; and

(ii) request or require such information from another health plan, or health insurance issuer, or provider of health care items and services.

"(C) The provisions of paragraphs (1) and (2) shall not apply if the individual, or the individual's legal representative, provides prior written authorization of such disclosure.".

(3) DEFINITIONS.—Section 2791(d) of such Act (42 U.S.C. 300gg-91(d)) is amended by adding at the end the following new paragraphs:

"(15) FAMILY MEMBER.—The term 'family member' means, with respect to an individual, a spouse or adopted child of that individual, or another individual related by blood to that individual or to a spouse or adopted child of that individual.

"(16) GENETIC INFORMATION.—The term 'genetic information' means information about genes, gene products, or inherited characteristics that may derive from an individual or a family member.

"(17) GENETIC SERVICES.—The term 'genetic services' means health services provided to obtain, assess, and interpret genetic information for diagnostic and therapeutic purposes, and for genetic education and counselling.".

(b) AMENDMENT RELATING TO THE INDIVIDUAL MARKET.—Subpart 3—Other Requirements of part B of title XXVII of such Act is amended by inserting after section 2751 (42 U.S.C. 300gg-51) the following new section:

"SEC. 2752. PROHIBITION OF HEALTH INSURANCE DISCRIMINATION ON THE BASIS OF GENETIC INFORMATION.

"(a) IN GENERAL.—Except as provided in subsection (b), the prohibitions of—

"(1) discrimination based on genetic information or request for or receipt of genetic services, and

"(2) collection of genetic information by a health insurance issuer, or disclosure of genetic information by or to such an issuer,

shall apply to a health insurance issuer offering coverage in the individual market to the same extent as they apply pursuant to section 2702 to a health insurance issuer subject to section 2702.

"(b) EXCEPTION.—The provisions of subsection (a) shall not prevent a health insurance issuer subject to subsection (a) from—

"(1) requesting or requiring disclosure of genetic information about an individual who is a participant or beneficiary (or an applicant for coverage as a participant or beneficiary) relating to a disease or condition for which the individual has been positively diagnosed or has received treatment at any time;

"(2) requesting an individual, as a condition for initial enrollment, to undergo a physical examination or related tests to determine whether the individual has a disease or condition; or

"(3) using information specified in paragraph (1) or the results of an examination or test specified in paragraph (2) to deny or vary the terms and conditions of health insurance benefits or coverage.".

(c) AMENDMENT CONCERNING MEDIGAP.—Section 2791(c)(4) of such Act (42 U.S.C. 300gg-91(c)(4)) is amended by inserting "except for purposes of sections 2702(a)(1)(F), 2702(c), and 2752" after "Social Security Act)".

(d) TECHNICAL AMENDMENT.—Title XXVII of such Act is amended in the subpart heading following section 2744 (42 U.S.C. 300gg-44) by striking "Subpart 3" and inserting "Subpart 2".

(e) EFFECTIVE DATE.—The amendments made by subsections (a) through (d) shall apply with respect to

(1) group health plans and group health insurance coverage for plan years beginning, and

(2) health insurance available or in effect in the individual market,

after 1 year after the date of enactment of this Act.

SEC. 4. AMENDMENTS TO INTERNAL REVENUE CODE OF 1986.

(a) PROHIBITION OF HEALTH INSURANCE DISCRIMINATION ON THE BASIS OF REQUEST FOR OR RECEIPT OF GENETIC SERVICES.—

(1) NO ENROLLMENT RESTRICTION FOR GENETIC SERVICES.—Section 9802(a)(1)(F) of the Internal Revenue Code of 1986 is amended by inserting before the period "or request for or receipt of genetic services".

(2) NO DISCRIMINATION IN GROUP RATE BASED ON GENETIC INFORMATION.—Section 9802(b)(1) of such Code is amended

(A) by striking "may not require any individual" and inserting "may not—

(A) require any individual";

(B) by moving the remainder of the paragraph two ems to the right;

(C) by striking the period and adding "; or"; and

(D) by adding at the end the following new subparagraph:

"(B) adjust premium or contribution rates for a group or the individuals in a group on the basis of genetic information concerning or a request for or receipt of genetic services by any member of such group or a covered dependent of such member.".

(b) LIMITATION ON COLLECTION AND DISCLOSURE OF GENETIC INFORMATION.—Section 9802 of such Code is amended by adding after subsection (b) the following new subsection:

"(c) WITH RESPECT TO COLLECTION AND DISCLOSURE OF GENETIC INFORMATION.—

"(1) COLLECTION.—Except as provided in paragraph (3), a group health plan, or a health insurance issuer offering health insurance coverage in connection with a group health plan, shall not request or require disclosure of genetic information concerning an individual who is a participant or beneficiary (or an applicant for coverage as a participant or beneficiary).

"(2) DISCLOSURE.—Except as provided in paragraph (3)—

"(A) a group health plan, or a health insurance issuer offering health insurance coverage in connection with a group health plan, shall not disclose genetic information about an individual who is a participant or beneficiary (or an applicant for coverage as a participant or beneficiary) to any other health plan or health insurance issuer or to the plan sponsor or plan administrator; and

"(B) a physician, hospital, or other person that provides health care items or services to an individual shall not disclose genetic information about such individual to any group health plan, or health insurance issuer offering health insurance coverage in connection with a group health plan.

"(3) EXCEPTIONS.--

"(A) The provisions of paragraphs (1) and (2) shall not apply to a request by or disclosure to a health plan or issuer that provides reasonable assurances that it provides health insurance coverage to such individual and requires such information for payment of claims or coordination of benefits.

"(B) Notwithstanding paragraphs (1) and (2), a health plan or issuer that provides health care items and services and provides reasonable assurances that it requires such information for diagnosis or treatment of such individual may—

(i) request (but not require) disclosure of such information by the individual; and

(ii) request or require such information from another health plan, or health insurance issuer, or provider of health care items and services.

"(C) The provisions of paragraphs (1) and (2) shall not apply if the individual, or the individual's legal representative, provides prior written authorization of such disclosure.".

(c) DEFINITIONS.—Section 9805(d) of such Code is amended by adding at the end the following new paragraphs:

"(6) FAMILY MEMBER.—The term 'family member' means, with respect to an individual, a spouse or adopted child of that individual, or another individual related by blood to that individual or to a spouse or adopted child of that individual.

"(7) GENETIC INFORMATION.—The term 'genetic information' means information about genes, gene products, or inherited characteristics that may derive from an individual or a family member.

"(8) GENETIC SERVICES.—The term 'genetic services' means health services provided to obtain, assess, and interpret genetic information for diagnostic and therapeutic purposes, and for genetic education and counselling.".

(d) EFFECTIVE DATE.—The amendments made by this section shall apply with respect to group health plans and group health insurance coverage for plan years beginning after 1 year after the date of the enactment of this Act.

[NOTE: TECHNICAL AND CONFORMING AMENDMENTS WILL BE NEEDED]

Health - genetic screening

PREVENTING INSURANCE DISCRIMINATION BASED ON GENETIC INFORMATION

In his commencement address at Morgan State University today, the President highlighted the great potential and possible perils of recent advances in genetic research. To address widespread concerns about potential abuses, the President Clinton called upon Congress to pass bipartisan legislation that would prohibit insurance companies from using genetic information to determine premium rates or eligibility for health plans.

ADVANCES IN SCIENCE: POTENTIALS AND PERILS

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. But genetic testing also can be used by insurance companies and others to discriminate and stigmatize groups of people. We know that genetic information has been used to discriminate against people in the past. In the early 1970's, health insurance coverage and jobs were denied to many African-Americans who were identified as carriers of sickle-cell anemia. Studies have shown that many Americans are extremely concerned with the possibility that their genetic makeup will be used to discriminate against them or a member of their family.

ADDITIONAL PROTECTIONS NEEDED

The new legislation will build on the important anti-discrimination insurance laws in the Health Insurance Portability and Accountability Act of 1996 (HIPAA). It would strengthen HIPAA by ensuring that in all cases genetic information will not be inappropriately used or disclosed by health plans. This would not only apply to health plans covered under ERISA but also provides blanket protections for all Americans who purchase individual policies.

More than a dozen states have already enacted laws to restrict the use of genetic information in health insurance and at least thirty-one others have introduced legislation in 1997. However, state legislation is insufficient to solve this problem. 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 LEGISLATION

Several bills have been introduced in this Congress, which prohibit health plans from requesting or using genetic information as a basis to deny health care coverage or raise premiums. The President believes that the bipartisan legislation introduced by Rep. Louise Slaughter, H.R. 306, represents a strong foundation for this much-needed reform. The Slaughter bill contains strict protections against disclosure of an individual's genetic information by health plans. The President looks forward to working with Rep. Slaughter and other members in both parties to pass legislation on this important issue in this Congress.

Health - genetic screening

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Health-genetic screening

QUESTIONS AND ANSWERS ON GENETIC TESTING

Q: DIDN'T WE ALREADY TAKE CARE OF THIS PROBLEM IN THE KASSEBAUM-KENNEDY HEALTH REFORM LEGISLATION?

A: The Kassebaum-Kennedy legislation did take important steps to prevent health insurers from discriminating on the basis of genetic information. However, this legislation builds on these provisions in three important areas: (1) prevents insurers in the individual market from discriminating on the basis of genetic information (2) assures the premiums setting is in no way based on genetic information both in the group and individual market; and (3) prevents insurance from disclosing genetic information.

- **Access in the Individual Market.** The Kassebaum-Kennedy law says that employers may not use genetic information as a pre-existing condition unless the illness associated with the pre-existing condition has already been diagnosed. In that case, the health plan could deny health care coverage for a maximum of twelve months.

  However, Kassebaum-Kennedy did not address the issue of genetic information for Americans who are part of the individual insurance market. This legislation would take the next step by protecting Americans who have an health insurance in the individual market from being denied health care coverage based on their genetic information.

- **Affordability in the Individual and the Group Market.** The Kassebaum-Kennedy legislation did not address the issue of affordability in the insurance market. Thus it does not prevent insurers from increasing group premium rates based on knowledge about genetic information. (It would prevent health plans from charging an individual higher premiums based on their genetic information).

  This new legislation would prevent health plans from setting premium rates based on genetic information, both in group health plans and in the individual market.

- **Disclosing Genetic Information.** This new legislation would also prevent health plans from releasing genetic information. If genetic information from health plans were accessible, it would make it much easier for other parties (probably employers and other non-health insurers) to misuse this information.

Q: AREN'T LOTS OF STATES TAKING ACTION ON THIS ISSUE. WHY DO WE NEED FEDERAL LEGISLATION?

A: More than a dozen states have taken action in this area and 31 more have proposed legislation. others have introduced legislation in 1997. However, state legislation is insufficient to solve this problem. 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. Moreover, Employer Retirement Income Security Act (ERISA) exempts self-funded plans from state insurance laws. Thus even if states enact legislation to build on Kassebaum-Kennedy legislation, a large fraction of the population in self-funded plans would not be protected.

Q: IS THERE ANY EVIDENCE THAT INSURANCE COMPANIES ARE DISCRIMINATING AGAINST PEOPLE WITH A GENETIC PREDISPOSITION TO A DISEASE?

A: Medical researchers and physicians have reported that people are refusing to get genetic testing or to participate in medical research because they fear that this information could be used against them or a member of their family. We know that genetic information has been used to discriminate against people in the past. In the early 1970's, health insurance coverage and jobs were denied to many African-Americans who were identified as carriers of sickle-cell anemia. We also know that a leading reason women refuse genetic testing for breast cancer is because they fear that insurance companies may deny health care coverage for either themselves or members of their families or charge excessively high premiums. Moreover, 22 percent of people who live in families where someone has a genetic disorder report that they have been discriminated against by an insurance plan. (Lapham et al., Science, Oct 1996).

Q: HOW WAS GENETIC TESTING USED IN THE 1970s TO DISCRIMINATE AGAINST AFRICAN-AMERICANS?

A: Genetic testing was used both by employers and health insurance plans to discriminate against African-Americans who had one or two altered copies of the sickle cell gene. There were newborn screening programs, pre-employment tests done, and other widespread screening done to test for this genetic disorder. However, most people mistakenly believed that if an individual had at least one altered gene, they would likely develop sickle cell anemia. In fact, both of the genes must be altered to be vulnerable to this disorder.

Q: THERE ARE LOTS OF BILLS OUT ON THE HILL ON THIS ISSUE. WHY DOES THE PRESIDENT LIKE THE ONE INTRODUCED BY REPRESENTATIVE SLAUGHTER?

A: The Slaughter Bill is based on the joint recommendations made by the National Institutes of Health's Working Group on Ethical, Legal, Social Implications of Human Genome Research (ELSI Working Group) and the National Action Plan on Breast Cancer (NAPBC) to address the issue of genetic discrimination and health insurance. It addresses all of the central issues: using genetic information to deny or limit any coverage; establishing premium payments based on genetic information or an individual's request for genetic information; and disclosure of genetic information.

Q: HOW MUCH WOULD THIS LEGISLATION COST?

A: We do not have any formal estimates on how much this legislation would cost. However, states who have enacted legislation in this area have not experienced any major costs associated with this.

Q: HOW MANY AMERICANS WOULD BE AFFECTED BY THIS LEGISLATION?

A: This legislation would protect all Americans from having to pay higher premiums based on genetic information and from having their genetic information disclosed.

Health-genetic screening

Genetic Screening Protection Legislation Would:

1) Prohibit insurers and other health plans from using genetic information, or an individual's request for genetic services, to deny or limit any coverage or establish eligibility for insurance.

2) Prohibit health plans from establishing differential rates or premium payments for individual insurance policies or group-wide plans based on genetic information.

3) Prohibit health plans from requesting or requiring collection or disclosure of genetic information.

4) Prohibit health plans or other holders of genetic information from releasing genetic information without prior written authorization of the individual.

Health - genetic screening

COSPONSORS OF H.R. 306, THE GENETIC INFORMATION NONDISCRIMINATION IN HEALTH INSURANCE ACT

(Total 98)

Rep. Neil Abercrombie
Rep. Gary Ackerman
Rep. Tom Barrett
Rep. Howard Berman
Rep. Rick Boucher
Rep. Corrine Brown
Rep. George Brown
Rep. Benjamin Cardin
Rep. Julia Carson
Rep. Donna Christian-Green
Rep. Eva Clayton
Rep. John Conyers
Rep. Bill Coyne
Rep. Pat Danner
Rep. Danny Davis
Rep. Peter DeFazio
Rep. Diana DeGette
Rep. William Delahunt
Rep. Rosa DeLauro
Rep. Ron Dellums
Rep. Anna Eshoo
Rep. Lane Evans
Rep. Eni Faleomavaega
Rep. Chaka Fattah
Rep. Bob Filner
Rep. Tom Foglietta
Rep. Jon Fox
Rep. Barney Frank
Rep. Martin Frost
Rep. Elizabeth Furse
Rep. Sam Gejdenson
Rep. Henry Gonzalez
Rep. Gene Green
Rep. Luis Gutierrez
Rep. Alcee Hastings
Rep. Bill Hefner
Rep. Earl Hilliard
Rep. Maurice Hinchey
Rep. Tim Holden
Rep. Steve Horn
Rep. Jesse Jackson, Jr.
Rep. Sheila Jackson-Lee
Rep. Nancy Johnson
Rep. Joe Kennedy
Rep. Dale Kildee
Rep. John LaFalce
Rep. Nick Lampson
Rep. John Lewis
Rep. Frank LoBiondo
Rep. Zoe Lofgren
Rep. Nita Lowey
Rep. Carolyn Maloney
Rep. Edward Markey
Rep. Matthew Martinez
Rep. Robert Matsui
Rep. Carolyn McCarthy
Rep. Jim McDermott
Rep. John McHugh
Rep. James McGovern
Rep. Cynthia McKinney
Rep. Marty Meehan
Rep. Carrie Meek
Rep. David Minge
Rep. Patsy Mink
Rep. James Moran
Rep. Connie Morella
Rep. Jerrold Nadler
Rep. Richard Neal
Rep. Eleanor Holmes Norton
Rep. James Oberstar
Rep. John Olver
Rep. Frank Pallone
Rep. Donald Payne
Rep. Nancy Pelosi
Rep. John Edward Porter
Rep. Lynn Rivers
Rep. Marge Roukema
Rep. Lucille Roybal-Allard
Rep. Bobby Rush
Rep. Loretta Sanchez
Rep. Bernie Sanders
Rep. Charlie Schumer
Rep. Jose Serrano
Rep. Christopher Smith
Rep. Pete Stark
Rep. Louis Stokes
Rep. Ellen Tauscher
Rep. Bennie Thompson
Rep. Karen Thurman
Rep. John Tierney
Rep. Esteban Torres
Rep. Edolphus Towns
Rep. Jim Traficant
Rep. Maxine Waters
Rep. Mel Watt
Rep. Henry Waxman
Rep. Albert Wynn
Rep. Sidney Yates

THE FOLLOWING GROUPS HAVE ENDORSED H.R. 306, THE GENETIC INFORMATION NONDISCRIMINATION IN HEALTH INSURANCE ACT OF 1997

Alliance for Aging Research
Alzheimer's Association
American Academy of Family Physicians
American Academy of Neurology
American Academy of Pediatrics
American Cancer Society
American Heart Association
American Medical Women's Association
American Nurses Association
American Public Health Association
Amyotrophic Lateral Sclerosis Association
Association of Women's Health, Obstetric and Neonatal Nurses
Cardiac Arrhythmia Research and Education Foundation
Center for Patient Advocacy
Coalition for Heritable Disorders of Connective Tissue
Cooley's Anemia Foundation
Council for Responsible Genetics
Cystic Fibrosis Foundation
Dysautonomia Foundation
Dystonia Medical Research Foundation
Epilepsy Foundation of America
Hemochromatosis Foundation, Inc.
International Patient Advocacy Association
Jeffrey Modell Foundation
Leadership Conference of National Jewish Women's Organizations, which includes:
    American Jewish Congress
    Amit Women
    B'nai B'rith
    Emunah Women of America
    Hadassah
    Jewish Labor Committee
    Jewish War Veterans
    Jewish Women International
    Na'amat USA
    National Council of Jewish Women, Inc.
    National Jewish Community Relations Advisory Council
    Union of American Hebrew Congregations
    Women's American ORT
    United Synagogue of Conservative Judaism
Leukemia Society of America
March of Dimes
National Breast Cancer Coalition
National Hemophilia Foundation
National Industries for the Blind
National Marfan Foundation
National Multiple Sclerosis Society
National Neurofibromatosis Foundation
National Organization for Rare Disorders
National Osteoporosis Foundation
National Ovarian Cancer Coalition
National Tuberous Sclerosis Association
National Women's Health Network
National Women's Law Center
Osteogenesis Imperfecta Foundation
Public Citizen
Sjogren's Syndrome Foundation
Spina Bifida Association of America
Spondylitis Association of America
Sturg-Weber Foundation
Tourette Syndrome Foundation
Wilson's Disease Foundation
Women's Bar Association
Women's Legal Defense Fund