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## THE GENETIC NONDISCRIMINATION IN HEALTH INSURANCE AND EMPLOYMENT ACT: H.R. 602

Congresswoman Louise Slaughter

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## Symposium

### **The Genetic Nondiscrimination in Health Insurance and Employment Act: H.R. 602**

*Congresswoman Louise Slaughter\**

Good afternoon! I am delighted to join you for today's symposium, "Personal Genetic Information: Implications for the Workplace and Criminal Justice." I would like to extend a special thanks to New York Law School and its *Journal of Human Rights* for inviting me to participate.

Let us then dive right into the matter at hand: the ethical, legal, and social implications of genetic research, and its consequences for public policy. I will explore three areas: the current situation and need for legislation; my proposal to ban genetic discrimination; and the outlook for Congressional action on my bill. I will then invite each of you to be part of the solution to end genetic discrimination in health insurance and employment.

#### THE PROBLEM AND THE NEED FOR LEGISLATION

Most of us would agree at the outset that genetic discrimination is wrong.<sup>1</sup> This being law school, however, we will make no assumptions and lay out a clear and cogent argument. Let me take a few moments to explain four key reasons why I believe discrimination based on predictive genetic information should be illegal.

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<sup>1</sup> See 42 U.S.C. § 1981 (2001) (federal law protecting certain individual rights against non-governmental discrimination and discrimination under color of state law). The Supreme Court has found that § 1981 protects at least discrimination directed against an individual based on being part of a genetically distinctive ethnic and physiognomic group of homo-sapiens. See *Saint Francis College v. Al-Khazraji*, 481 U.S. 604 (1987). Discrimination based on factors including genetic predisposition is explicitly proscribed in New York's Human Rights Law. See N.Y. EXEC. L. § 296 (2001).

1. *Genetic science is not yet fully understood.* Immediately following the discovery of the first breast cancer gene, scientists estimated that having this gene conferred an 85% risk of developing breast cancer.<sup>2</sup> Within two years, however, the risk had been downgraded to only 50 percent.<sup>3</sup> Over time, we will further refine our understanding of these and other genes, as well as the interplay among genes and the impact of the environment. Using genetic information to discriminate at this point in time is so inaccurate as to be almost useless<sup>4</sup> — especially in the context of determining who should get a job, or who should be eligible for affordable insurance.

2. *Having a predictive gene does not necessarily mean you will ever get sick.* And even if you do, the disorder might not develop for 10, 20, or 30 years.<sup>5</sup> No one should be passed over for a promotion at work or lose their insurance coverage simply because they *might* get sick *someday*.

3. *We all have genetic flaws.* Dr. Francis Collins, Director of the National Human Genome Research Institute, is frequently quoted as saying every human being is estimated to have between 5 and 50 significant genetic mutations, making us all ultimately unemployable and uninsurable.<sup>6</sup> By allowing genetic discrimination to persist, we effectively penalize the people who happen to have the genes that were discovered first.<sup>7</sup>

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<sup>2</sup> See Thomas H. Maugh II, *Discovery of Breast Cancer Gene Called Major Advance*, L.A. TIMES, September 15, 1994, at 1. See also *OncorMed Licenses Genetic Markers for Breast and Ovarian Cancer from the University of California*, BIOTECH PATENT NEWS, No. 9, Vol. 10, Sept. 1, 1996.

<sup>3</sup> See Stephanie Slon, *The Breast Cancer Gene*, (1999) available at <http://www.cnn.com/HEALTH/cancer/9905/26/breast.cancer.gene>; see also JOAN SWIRSKY AND BARBARA BALABAN, *THE BREAST CANCER HANDBOOK – TAKING CONTROL AFTER YOU’VE FOUND A LUMP*, at 124 (2<sup>nd</sup> Ed. 1998).

<sup>4</sup> Michael R. Costa, *Genetic Testing: International Strategies To Prevent Potential Discrimination In Insurance Risk Classification*, 20 SUFFOLK TRANSNAT’L L. REV. 109, 113 (1996); Natalie E. Zindorf, *Discrimination in the 21st Century: Protecting The Privacy Of Genetic Information In Employment and Insurance*, 36 TULSA L.J. 703 (2001).

<sup>5</sup> The ASHG Ad Hoc Committee on Breast & Ovarian Cancer Screening, *Statement of the American Society of Human Genetics on Genetic Testing for Breast & Ovarian Cancer Predisposition*, AM. J. GENET. 55 i-iv (1994).

<sup>6</sup> See e.g., *ABC Good Morning America* (ABC television broadcast, Sept. 30, 1998) (statement by Francis Collins directly on point).

<sup>7</sup> See e.g., Elaine Draper, *The Screening of America: The Social and Legal Framework of Employers’ Use of Genetic Information*, 20 BERKELEY J. EMPLOY-

4. *Both employers and insurers have managed to do just fine for many years without having access to genetic information.* In case you have not noticed, the insurance industry is highly profitable, and has been for decades.<sup>8</sup> Today, very little “individual underwriting” goes on<sup>9</sup> — that is, few people obtain insurance based on their own specific medical record. Most Americans receive their coverage through group plans that base rates on actuarial estimates of the incidence of health problems.<sup>10</sup> Furthermore, very little — if any — genetic information has **any** bearing on an individual’s ability to perform a given job.<sup>11</sup> Employment decisions should be based on a person’s job performance and merit, not his or her genes.

In the face of this uncertainty, the logical course is to ban all genetic discrimination, rather than allowing a “Wild West,” anything-goes atmosphere to prevail. The abuse of genetic information has the potential to destroy individuals’ careers and do long-term damage to their and their families’ health.<sup>12</sup> We must err on the side of caution and ban *all* genetic discrimination in health insurance and employment.

#### THE GENETIC NONDISCRIMINATION IN HEALTH INSURANCE AND EMPLOYMENT ACT

For all of these reasons, I am proud to be the author of H.R. 602, the Genetic Nondiscrimination in Health Insurance and Employment Act.<sup>13</sup> As its title suggests, the bill would prevent both

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MENT & LAB. L. 286, 315 (1999) (encouraging anti-discrimination laws to prevent penalizing individuals that are genetically predisposed).

<sup>8</sup> See e.g., David Wanetick, Chairman, *NYSSA 5<sup>th</sup> Annual Insurance Conference*, Jan. 29-30, 2001, at <http://www.nyssa.org/events/insurance2001.html> (last visited December 6, 2001).

<sup>9</sup> See Thomas H. Murray, *Genetics and the Moral Mission of Health Insurance*, HASTINGS CENTER REPORT, Vol. 22, No. 6, Nov. 1992, at 12; see also Peter Pockley, et al., *Insurers Inconsistent Over HIV*, BRIT. MED. J., Vol. 306, No. 6891, June 1993, at 1495.

<sup>10</sup> See Katharine R. Levit et al., *Nat’l Health Care Spending Trends*, 9 HEALTH AFF. 177, 177 (1990).

<sup>11</sup> See Tamar Lewin, *Commission Sues Railroad to End Genetic Testing in Work Injury Cases*, N.Y. TIMES, Feb. 10, 2001, at A10.

<sup>12</sup> See *Researchers Find Signs of Genetic Discrimination by Insurers*, FEDERAL & STATE INSURANCE WEEK, No. 14, Vol. 10, April 15, 1996.

<sup>13</sup> H.R. 602, 107<sup>th</sup> Cong. § 714 (d) (2001); S. 318, 107<sup>th</sup> Cong. § 714 (d) (2001).

health insurance companies and employers from using genetic information to discriminate against individuals.

With regard to health insurance discrimination, H.R. 602 would:

- cover all health insurance programs, including those regulated by the federal government, state-regulated plans, and the individual market;
- prohibit insurers from restricting enrollment or changing premiums on the basis of predictive genetic information or genetic services;
- ban health plans and insurers from requesting or requiring that an individual take a genetic test, or reveal the results of such a test; and
- prohibit health plans and insurers from pursuing or being provided information on predictive genetic information or genetic services.<sup>14</sup>

With regard to employment discrimination, H.R. 602 would:

- cover employers, employment agencies, labor organizations, and training programs;
- prevent discrimination in hiring, compensation, and other personnel processes;
- prohibit employers from requiring or requesting disclosure of predictive genetic information, and allow genetic testing only to monitor the adverse effects of hazardous workplace exposures; and
- require predictive information possessed by employers to be confidentially maintained and disclosed only to the employee upon request, or to researchers (under strict guidelines).<sup>15</sup>

Both health insurance and employers would be subject to stiff penalties for violating either the nondiscrimination or privacy provisions of this law.<sup>16</sup> The Secretary of Health and Human Services may impose civil money penalties, and individuals may pursue a private right of action.<sup>17</sup> Without such sanctions, including the right to sue, the law becomes little more than a paper tiger. Strong en-

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<sup>14</sup> H.R. 602, 107<sup>th</sup> Cong. § 714 (d) (2001); S. 318, 107<sup>th</sup> Cong. § 714 (d) (2001).

<sup>15</sup> H.R. 602, 107<sup>th</sup> Cong. § 714 (d) (2001); S. 318, 107<sup>th</sup> Cong. § 714 (d) (2001).

<sup>16</sup> H.R. 602, 107<sup>th</sup> Cong. § 714 (d) (2001); S. 318, 107<sup>th</sup> Cong. § 714 (d) (2001).

<sup>17</sup> H.R. 602, 107<sup>th</sup> Cong. § 714 (d) (2001); S. 318, 107<sup>th</sup> Cong. § 714 (d) (2001).

forcement provisions are necessary to show that Congress is serious about this matter.

I am pleased to report that H.R. 602 has 255 bipartisan cosponsors, including 50 Republicans, representing well over half of the House of Representatives (58%).<sup>18</sup> An identical bill (S. 318) has been introduced in the Senate by Minority Leader Tom Daschle and Senators Edward Kennedy, Tom Harkin, and Christopher Dodd.<sup>19</sup> Our legislation has the support of over 100 organizations, ranging from the American Cancer Society to the National Breast Cancer Coalition to the American Academy of Pediatrics.

I wish I could say that this bill was prophylactic — that we had not seen incidences of genetic discrimination arise yet. Unfortunately, this is not the case. Allow me to share a few true stories with you:

\* \* \*

A woman took a genetic test for breast cancer based on numerous cases among her family members and learned that she did indeed carry the gene. She decided to have a prophylactic double mastectomy and petitioned her insurer to cover the procedure without sharing the genetic information. When the insurance company denied her request, she revealed to them that she had the breast cancer gene. Upon learning this information, the insurer not only denied her request, but canceled her policy as well.<sup>20</sup>

\* \* \*

Terri had received outstanding job evaluations and regular, generous raises for years. Upon going to the doctor for allergy problems, however, she was diagnosed with Alpha1, a disease that had killed her brother. She began a regimen of treatments that would keep her healthy and functional, carefully scheduling her appointments on evenings, weekends, and vacation time. When her self-insured employer learned about her condition, she was told that her ser-

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<sup>18</sup> Press Release, Senator Tom Daschle, Daschle Welcomes President Bush to the Fight to Protect Americans from Genetic Discrimination *available at* <http://daschle.senate.gov/~daschle/pressroom/releases/01/06/2001627652.html> (last visited June 25, 2001).

<sup>19</sup> *Id.*

<sup>20</sup> Press Release, Senator Tom Daschle, Daschle Remarks Prepared for Delivery by Senate Democratic Leader Tom Daschle on the Introduction of the Genetic Nondiscrimination in Health Insurance and Employment Act <http://daschle.senate.gov/~daschle/pressroom/releases/01/06/2001627652.html> (last visited Feb. 13, 2001).

VICES were no longer needed and was asked to leave. The Equal Employment Opportunity Commission is now suing Terri's employer on her behalf, alleging genetic discrimination.<sup>21</sup>

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As some of you may have seen in the news earlier this year, the Burlington Northern Santa Fe Railroad was also sued by the EEOC for genetic discrimination.<sup>22</sup> Workers filing disability claims related to carpal tunnel syndrome were being tested *without their knowledge or consent* for an extremely rare genetic condition that may predispose some individuals to the disorder.<sup>23</sup> The company evidently hoped to avoid paying disability claims for any workers found to have the gene.<sup>24</sup>

Cases like these serve as a warning shot across our bow, foreshadowing more numerous and egregious cases of genetic discrimination in the future. As it is, the fear of genetic discrimination is growing pervasive.<sup>25</sup> When I speak with scientists engaged in genetic research, they tell me that it is growing increasingly difficult to recruit participants for these studies. Even when confidentiality is going to be rigorously protected, too many candidates still fear that their genetic information could get out and be used against them.<sup>26</sup>

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<sup>21</sup> *Genetic Information in the Workplace: Hearing of the Senate Comm. on Health, Education, Labor, and Pensions*, 106th Cong. 80-81 (2000)(statement of Terri Seargent), available at [http://www.alpha1.org/programs/newsmakers\\_seargent.htm](http://www.alpha1.org/programs/newsmakers_seargent.htm); *What Every Woman Should Know About Genetic Discrimination*, NAT'L PARTNERSHIP, available at <http://www.nationalpartnership.org/download/geneticguide.txt> (last visited Nov. 26, 2001).

<sup>22</sup> Darryl Van Duch, *EEOC Goes After Genetic Testing*, NAT'L L.J., May 7, 2001, at B1; Steven Seidenberg, *Mapping the Path of Genetic Bias Law*, MIAMI DAILY BUS. REV., Aug. 15, 2001, at 9.

<sup>23</sup> Cheye Calvo, *From Laboratories to Legislatures . . . (Laws on Genetic Testing)*, STATE LEGISLATURES, September 1, 2001, No. 8, Vol. 27, at 26; Steven Seidenberg, *Mapping the Path of Genetic Bias Law*, MIAMI DAILY BUS. REV., Aug. 15, 2001, at 9.

<sup>24</sup> *60 Minutes II* (CBS television broadcast, Apr. 10, 2001).

<sup>25</sup> *Genetic Information in the Workplace: Hearing of the Senate Comm. on Health, Education, Labor, and Pensions*, 106th Cong. 3-30 (2000) (statement of Steven Paul Miller, Commissioner, U.S. Equal Employment Opportunity Commission); Paul S. Miller, *Is There a Pink Slip in My Genes? Genetic Discrimination in the Workplace*, 3 J. HEALTH CARE L. & POL'Y 225, 232-238 (2000).

<sup>26</sup> See e.g., Gina Kolata, *Ticking Bomb: The Presence of a Breast-Cancer Gene Creates Other Problems for Some Women*, CHICAGO TRIBUNE, April 13, 1997 at 6.

Furthermore, many Americans are deciding not to take genetic tests due to their fear of discrimination.<sup>27</sup> I have spoken to numerous people at conferences and other gatherings who come up to me after my remarks and tell me that they would like to take a genetic test for cancer or Alzheimer's, but that they fear the information will not remain private. **It is unconscionable that people are being forced to deny themselves valuable health information simply because Congress has not acted to ban genetic discrimination.**

#### THE PROSPECTS FOR ACTION

I hope you are all convinced by now that Congress must act to ban genetic discrimination as soon as possible. The critical question is, how likely is that to happen?

We face a daunting challenge. Although hard to believe, H.R. 602 has opposition that cannot be underestimated.<sup>28</sup> First and foremost, the health insurance industry opposes this legislation.<sup>29</sup> Although they do not say so publicly, the insurance industry would like very much to have access to genetic information.<sup>30</sup> Since every one of us has genetic flaws and could therefore ultimately be uninsurable, this might not seem to make much sense. However, health insurers know that most people carry a given policy only for a few years.<sup>31</sup> If they can determine whether a person might get seriously ill in less than five years, this information could potentially have a great benefit for the bottom line<sup>32</sup> — but it would be devastating for all the individuals who lose their insurance coverage just when they need it the most.<sup>33</sup>

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<sup>27</sup> Wendy Lovejoy, *Ending the Genetic Discrimination Barrier: Regaining Confidence in Preconception, Prenatal, and Neonatal Genetic Testing*, 74 S. CAL. L. REV. 873, 890 (2001).

<sup>28</sup> See e.g., William Roberts, *Daschle Urges U.S. Senate Panel to Ban Genetic Discrimination*, BLOOMBERG NEWS, July 25, 2001 (indicating that the Biotechnology Industry Organization, the Health Insurance Association of America, and the U.S. Chamber of Commerce oppose the bill).

<sup>29</sup> *Genetic Discrimination: Venter, Industry Face Off On Bill*, AMERICAN HEALTH LINE, July 12, 2001; *Congress Inclined to Bar Gene Testing*, INSURANCE CHRONICLE, July 16, 2001, Vol. 12, No. 29, at 1.

<sup>30</sup> Larry R. Churchill, *We Are Our Genes—Not! How Will Genetic Tests Be Used?* WORLD AND I MAGAZINE, Nov. 1, 2001, Vol. 16, No. 11, at 156; Steven Brostoff, *Patients' Bill Of Rights Could Be A Warm-Up For Emotional Genetic Testing Issue*, NAT'L UNDERWRITER, July 16, 2001, at 58.

<sup>31</sup> *Congress Inclined to Bar Gene Testing*, *supra* note 29.

<sup>32</sup> See Brostoff, *supra* note 30.

<sup>33</sup> See Brostoff, *supra* note 30; see also Churchill, *supra* note 30.

In addition, some pharmaceutical companies have concerns about H.R. 602.<sup>34</sup> They support the genetic nondiscrimination provisions with great enthusiasm — after all, if people cannot get health insurance, they will not be able to afford the new genetic therapies these companies are developing.<sup>35</sup> But the pharmaceutical industry balks at the modest privacy protections included in the bill.<sup>36</sup> According to one drug company representative, these corporations would ultimately like to “partner” with HMOs and others to browse through patients’ records, identify those with certain genetic information or predispositions, and then market their products directly to those individuals.<sup>37</sup> As a lawmaker, I have profound concerns about the implications of a practice like this for patient privacy, the delivery of health care, and the potential increased costs to government programs like Medicare and Medicaid.

With regard to employment discrimination, large employer groups like the Chamber of Commerce and the National Association of Manufacturers have expressed concerns with certain parts of the employment sections of H.R. 602.<sup>38</sup> While it is unclear when or whether we might be able to reach agreement, I am heartened that these groups have not opposed my bill outright. Cases like Burlington Northern Santa Fe have made it more difficult for employers to argue that nondiscrimination protections are unnecessary or counterproductive.

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<sup>34</sup> *Genetic Discrimination: Hearing Before the Subcommittee on Employer-Employee Relations*, July 24, 2001, (testimony of Harold Coxson, Esq.) available at <http://edworkforce.house.gov/hearings/107th/eed/genetic72401/coxson.htm>.

<sup>35</sup> See generally, Angela Liang, *Gene Therapy: Legal and Ethical Issues for Pregnant Women*, 47 CLEV. ST. L. REV. 61 (1999) (discussing the implications of the lack of opportunity for genetic testing for low income pregnant women without health insurance); see Wendy Lovejoy, *Ending the Genetic Discrimination Barrier: Regaining Confidence in Preconception, Prenatal and Neonatal Genetic Testing*, 74 S. CAL. L. REV. 873, 892-893 (2001) (discussing the implications of lack of genetic testing for millions of uninsured children).

<sup>36</sup> Religious Action Center of Reform Judaism, *ISSUES: Privacy, Medical Records*, available at <http://www.rac.org/issues/issuepr.html>.

<sup>37</sup> See *Gene Issues Take Root; Government is Starting to Recognize The Potentially Enormous Societal Effects of New Discoveries and Devices*, L.A. TIMES, July 15, 2000, at B9 (voicing concern for financial conglomerates, consisting of insurers, investment companies and banks sharing genetic information).

<sup>38</sup> See generally *Genetic Information in the Workplace Hearing Before Senate Health, Education, Labor & Pensions*, 107<sup>th</sup> Cong. (2000) (statement of Harold P. Coxon, Shareholder in the National Labor and Employment Law Firm Ogletree, Deakins, Nash, Smoak & Stewart, P.C.) (discussing employment concerns with legislation concerning genetic testing).

These industries have extremely powerful allies in Congress.<sup>39</sup> As of July of this year, no standing committee of the U.S. House of Representatives had ever held a hearing on genetic discrimination issues. The chairmen of the oversight committees had bottled up not only my bill, but the entire issue. There is no doubt in my mind that groups like health insurers played a key role in those decisions.

In July, however, the situation changed.<sup>40</sup> Both the House Committee on Energy and Commerce and the Committee on Education and the Workforce held hearings on genetic discrimination.<sup>41</sup> This newfound interest in the issue seems to have stemmed, at least in part, from a June 23 radio address delivered by President Bush in which he called for legislation to ban genetic discrimination in health insurance and employment.<sup>42</sup>

Around the same time, another key circumstance changed in our favor: the Senate switched from Republican to Democratic control.<sup>43</sup> The Senate sponsors of my legislation are now the Majority Leader and Chairman of the committee of jurisdiction.<sup>44</sup> One hearing was held in July, but the second, scheduled for mid-September, was unfortunately derailed by the events of September 11.<sup>45</sup> Nevertheless, both Senators Daschle and Kennedy remain strongly committed to passage of this legislation.<sup>46</sup>

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<sup>39</sup> See Greg Gordon & Andrew Donohue, *Dozens in Congress Own Millions in Drug Stocks*, STAR TRIBUNE, Sept. 28, 2000, at 6A; see also *Drug Companies: Lobbying Spending Reaches All-Time High*, AMERICAN HEALTH LINE, July 7, 2000.

<sup>40</sup> See Erin Heath, *Zippering Up Genes Discrimination*, NAT'L J. Vol. 33, No. 29, July 21, 2001 see also Brostoff, *supra* note 30.

<sup>41</sup> *Genetic Non-Discrimination: Implications for Employers and Employees: Hearing Before the House Comm. on Education and the Workforce*, 107<sup>th</sup> Cong. (2001) (statement of Rep. Sam Johnson).

<sup>42</sup> See Karen Lee, *State, Local Governments Advance Employment Laws*, EMPLOYEE BENEFIT NEWS, Aug. 1, 2001.

<sup>43</sup> David Espo, *Senate Balance Switches as Jeffords resolves to leave GOP available at* <http://detnews.com/2001/politics/0105/23/-227599.htm> (last visited May 23, 2001).

<sup>44</sup> William Roberts, *supra* note 28; American Civil Liberties Union Press Release, *ACLU Urges Senate to Take Immediate Action to Protect Against Genetic Discrimination available at* <http://www.aclu.org/news/2000/n072000a.html> (last visited July 1, 2001).

<sup>45</sup> William Roberts, *supra* note 28 (July hearing on genetic discrimination).

<sup>46</sup> American Civil Liberties Union Press Release, *supra* note 44.

In the wake of that terrible tragedy, the legislative landscape has changed profoundly in Congress.<sup>47</sup> Very few initiatives outside funding bills and antiterrorism legislation are being considered. I am encouraged, though, that the committees have not completely abandoned this proposal. My office continues to engage in staff-level negotiations with the committees.<sup>48</sup>

No one can predict today what will happen in Congress next year. A great deal will depend upon whether further terrorist or bioterrorist attacks take place. In my view, however, it is critically important that Congress not lose sight of the *other* needs of the nation. Bills like H.R. 602 should not fall by the wayside simply because Congress is incapable of considering multiple priorities.

#### CONCLUSION

In conclusion, there is no question in my mind that we must ban genetic discrimination now or face terrible consequences in the future. If we allow genetic discrimination to become widespread and then try to ban the practice, we will find it all but impossible to put the genie back in the bottle.

The law is organic; it must change and adapt, just as individuals do, in times of need. This concept may have been expressed best by one of our nation's foremost legal minds, Thomas Jefferson, when he wrote the following in 1816:

I am certainly not an advocate for frequent changes in laws and constitutions. But laws and institutions must go hand in hand with the progress of the human mind. As that becomes more developed, more enlightened, as new discoveries are made, new truths discovered and manners and opinions change, with the change of circumstances, institutions must advance also to keep pace with the times. We might as well require a man to wear still the coat which fitted him when a boy as civilized society to remain ever under the regimen of their barbarous ancestors.<sup>49</sup>

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<sup>47</sup> *Events of September 11 Spur Custody Procedures, Altered Legislative Landscape*, 78 No. 37 INTERPRETER RELEASES 1493.

<sup>48</sup> *See generally id.*

<sup>49</sup> Thomas Jefferson Memorial Statute Chamber Inscriptions, July 1816, available at [www.nps.gov/thje/memorial/in.scrip.htm](http://www.nps.gov/thje/memorial/in.scrip.htm) (taken from a letter to Samuel Kercheval).

It is time for the United States to address the legal and ethical challenges raised by genetic research. I hope you will all work with me in ensuring that our nation passes a strong genetic nondiscrimination law.

