

TESTIMONY OF

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**HEARING BY THE HOUSE EDUCATION AND LABOR
SUBCOMMITTEE ON HEALTH, EMPLOYMENT, LABOR
AND PENSIONS**

TUESDAY, JANUARY 30, 2007

Chairman Andrews and members of the Subcommittee on Health, Employment, Labor and Pensions. My name is Harriet Pearson, and I serve as IBM's Chief Privacy Officer, and as Vice President of Corporate Affairs.

IBM appreciates the opportunity to testify in this hearing on H.R. 493, the Genetic Information Nondiscrimination Act of 2007. IBM supports the legislation.

IBM is a globally-integrated enterprise engaged in business and technology innovation with more than 340,000 employees. We provide access to healthcare coverage to more than 500,000 IBMers, their families and dependents.

On October 9, 2005, IBM became the first major corporation to make genetic non-discrimination part of our official employment policy. As our chairman, Sam Palmisano, said in his letter to employees:

“It has been IBM's long-standing policy not to discriminate against people because of their heritage or who they are. A person's genetic makeup may be the most fundamental expression of both. So we are taking this step today because it is the right thing to do – for the sake of the innovation that lies just over the horizon, and because it is entirely consistent with our values and with who we are as a company.”

(The entire note is attached as an appendix to this document.)

Reaction among IBM employees, health and privacy experts and others to our leadership on this issue has been uniformly positive. Let me cite two examples:

- An IBM software employee wrote: “you make me proud to be an IBM employee. I will be sharing this with my friends outside of IBM as an example of how my company can choose to put its people first and do the right thing.”
- One IBMer wrote to Sam Palmisano: “as a deaf employee, I would like to extend a deep and sincere thank you for ensuring that my rights are protected, even indirectly, through this policy.”

In our policy, IBM has taken the position that genetic information will not be used in hiring, in determining employees' eligibility for health care coverage or other employment benefits, or in other employment decisions to which such information is not relevant.

The reasons for making genetic privacy part of our broader discrimination protections were clear to us: first, we believe that a person's genetic profile or makeup should be treated the same as other innate human characteristics, such as one's race, gender, sexual orientation, age or physical abilities.

Simply stated, a person's genetic profile is as natural and as inseparable from whom they are as any other physical trait or attribute.

Common Genetic Tests Today	Emerging Tests and Genetic Screening
Huntington's Disease	Bowel Cancer (University of Edinburgh)
Cystic Fibrosis	Ocular Melanoma (UCLA's Jules Stein Eye Institute)
Breast Cancer, pre-symptomatic testing	Human Papillomavirus (Roche)
Prenatal Genetic Screening	Fragile X Syndrome (U.S. Genomics & Quest Diagnostics)
Pre-Implantation Testing of Embryos	Early Stage Lung Cancer (University of Maryland School of Medicine)

Second, it is even more important to protect people's genetic privacy as medicine and science further discover the relationship between specific diseases and an individual's unique genetic fingerprint.

We know this because IBM technology underlies many genetic breakthroughs from gene sequencing to personalized medicine.

For example, our experts in healthcare and life sciences are working with medical researchers at centers around the world, such as the Mayo Clinic and the Karolinska Institute in Sweden to harness genetic insights to unlock the molecular roots of disease.

One innovation front we are leading is to enable genetic data to be securely and anonymously integrated with other types of healthcare data such as electronic medical records. This approach holds considerable promise both for saving individual lives and for speeding medical breakthroughs.

Today, there are genetic tests for almost 1000 diseases¹, and several hundred more are under development. The results can help confirm conditions and inform treatment decisions. In other instances they can quantify the risk of future disease. Some genetic tests under development aim to predict the responsiveness of drugs for heart disease, cancer, asthma and other conditions.

The danger of not safeguarding genetic information is the potential that a person with a genetic predisposition toward one or more diseases might be denied healthcare insurance, lose their job or be turned down for one.

¹ The Genetics & Public Policy Center

Genetic data or tests results should also be shielded because in many instances they only suggest a risk of developing a disease. It is our view that no one should lose their health insurance or their livelihood because they have a statistical chance of becoming diabetic, arthritic or asthmatic. Instead, such information can be—and should be—used to the positive ends of enabling preventive lifestyle changes or potentially tailoring medical or pharmaceutical regimens that reduce the risk of the condition at issue developing.

As Francis Collins, Director of the National Human Genome Research Institute noted in 2003, in “A Brief Primer on Genetic Testing”:

Applied properly, [genetic testing] could usher in a new era of individualized preventive medicine that could have considerable health benefits. It will be important to remember, however, that most of these tests will not be "yes or no" but rather will predict relative risk. For this paradigm to succeed, it will also be essential that predictive genetic information is used to benefit individuals, rather than to injure them by discriminatory misuse.

There is little disagreement, we believe, in Congress or across the country, that each of us should be protected from discrimination based on genetic makeup. As we discovered in setting our own company-wide policy, there is value and security in clarifying that such discrimination will not be practiced or tolerated.

A powerful reason for Congress to act on genetic nondiscrimination now is that this issue is undoubtedly bound to become a bigger challenge as we move into the future of information-based medicine, where genetic screening or tests will be used even more routinely in the diagnosis and treatment of disease.

In fact, by setting a national policy that one’s genetic data should not lead to discrimination in the workplace and health insurance market, we may improve patient

"What I.B.M. is doing is significant because you have a big, leadership company that is saying to its workers, 'We aren't going to use genetic testing against you,'" said Arthur L. Caplan, director of the Center for Bioethics at the University of Pennsylvania medical school. "If you want a genomic revolution," Mr. Caplan added, "then you better have policies, practices and safeguards that give people comfort and trust."
The New York Times, October 10, 2005

care: people with genetic predispositions toward chronic diseases such as diabetes or heart disease could seek preventative treatment without fear of the consequences to their employment or access to health insurance.

By firmly establishing that none of us can be discriminated against on the basis of the genes we are born with and have no real control over, we also will create the safe foundation for future therapies that could repair or address the genetic defect that might make us prone to particular diseases or ailments.

The era of genetic medicine is probably closer than we think. In order for society to benefit from, and be prepared for, such profound innovations in healthcare, we need to create the social and legal environment that will be conducive to it.

When we instituted our policy in 2005, one of the biggest questions it raised was “why do we need such protections now, in advance of genetic discrimination being commonplace?”

For IBM, the answer was that matters of policy are not about reacting to external pressure, but following the logic of the company’s inherent values. From IBM’s early days, we instituted equal opportunity policies, policies that prohibit discrimination on the basis of race or gender for example, decades before they were mandated by law, because they were the right thing to do, because they were implicit in the company’s core values.

Today, two of IBM’s core values – values that were shaped by the entire IBM population via online collaborations called “jams” – provide clear direction for our path as an organization. Those values are ‘innovation that matters – for our company and for the world’ and ‘trust and personal responsibility in all relationships.’ In our view, not protecting IBMers’ genetic privacy or not including genetics in our equal-opportunity policy would have been inconsistent with our *own* DNA as an organization.

IBM Employment Policy Milestones

1914 – IBM hires its first employee with a disability

1953 – IBM establishes a formal equal opportunity policy

1984 – IBM adds sexual orientation to company policies regarding non-discrimination policy

2005 – IBM adds genetic privacy to company policies regarding non-discrimination policy

In addition, in the little more than a year since our announcement, new genetic markers for diseases such as diabetes, Alzheimer’s and others have demonstrated that we certainly weren’t too early.

In that light, it is the right time for Congress to address this issue head on, and make genetic discrimination part of the protections we as Americans have against biases that run counter to Americans’ shared values of fairness and merit-based decisionmaking.

IBM supports H.R. 493, The Genetic Nondiscrimination Act of 2007, and has the following practical observations to share:

- There is the potential for confusion or overlap because individuals could seek remedies for claims of genetic discrimination through the provisions in the legislation, as well as through existing legislation such as the Americans with Disabilities Act.

- Genetic information is defined broadly as the occurrence of a "disease or disorder in family members of an individual." That description may not reflect the increasingly unique, individual nature of genetic data and personalized medicine.
- Congress should also closely monitor implementation of the legislation by the responsible federal administrative agencies to ensure there are no expansive interpretations which could create unanticipated burdens on the employer community. Any legislation that includes new expansions in liability can create costs that are burdensome.

Protecting genetic privacy is an opportunity for our nation to lead on a front that is almost certain to become a global challenge, and for us to chart a course that expands the range of individual liberties that are at the heart of the American ideal.

There have been relatively few times in our history when the significance of a major technological breakthrough could be understood from the get-go. The times have been even fewer when societal and political conditions at that same moment were ripe for enlightened planning. We usually legislate by hindsight. Because we usually acquire the wisdom to shape and protect a scientific breakthrough only decades after it has broken through. Today, with this technology, with this issue, and with this legislation – properly improved – Congress has the chance to do so.

Thank you. And now I'm happy to answer any questions.

Appendix

SJP Comm/Somers/IBM

10/09/2005 06:26 PM

To:

IBMer US 0051, IBMer US 0052, IBMer US 0053, IBMer U

cc:

Subject:

Protecting Genetic Privacy

Dear IBMer:

During our lifetimes, the practice of medicine and society's approach to healthcare have changed in fundamental ways. But what lies ahead -- perhaps in the next decade alone -- seems likely to eclipse that progress dramatically.

Along with any change in an important area of science or society, new and often difficult policy questions inevitably arise. And that's uniquely so for healthcare. Business, government and the research community have a responsibility to address these issues. I am writing today to tell you about an important step that IBM is taking to do so.

Of all the work now taking place across the life sciences, none perhaps has the transforming potential of the pioneering efforts to unlock the secrets of the human genome. IBM is already engaged in many of the technology innovations springing from the revolution in genetics and IT -- from "information-based medicine" (which seeks to transform care by marrying genomics with clinical treatment); to our Genographic Project, where we're helping National Geographic to map the scientific history of our genes' migration; to the innovation flowing from our Blue Gene supercomputer.

This work is enormously promising -- but it also raises very significant issues, especially in the areas of privacy and security. The opportunity the world has to improve life in the century ahead through genomics-driven, personalized medicine and preventive care will only be realized fully if it also takes into account the protection of genetic privacy. We must make this a priority now.

For that reason, I have signed a revision of IBM's equal opportunity policy, first published by Thomas J. Watson, Jr., in 1953. IBM is formally committing that it will not use genetic information in its employment decisions, a policy we believe is [the first of its kind for a major corporation](#). You should know that IBM does not actively seek to collect genetic information -- but at times, and increasingly in the future, employees or their family members may choose to share it, for example, in order to facilitate participation in information-based wellness programs. In anticipation of such circumstances and other situations that we cannot fully anticipate, we are today establishing that business activities such as hiring, promotion and compensation of employees will be conducted without regard to a person's genetics.

It has been IBM's long-standing policy not to discriminate against people because of their heritage or who they are. A person's genetic makeup may be the most fundamental expression of both. So, we are taking this step today because it is the right thing to do -- for the sake of the innovation that lies just over the horizon, and because it is entirely consistent with our values and with who we are as a company.



Samuel J. Palmisano
Chairman and Chief Executive Officer