

SAMPLE HOUSE LETTER



21 April 2005

The Honorable Judy Biggert
US House of Representatives
1317 Longworth HOB
Washington, DC 20515

Dear Representative Biggert:

I am writing on behalf of The Institute of Electrical and Electronics Engineers-United States of America (IEEE-USA) and its Medical Technology Policy Committee to encourage House consideration and passage of H.R. 1227, the Genetic Information Nondiscrimination Act of 2005.

It is our position that the American public must be able to access the health benefits provided by genetic information without fear of consequent discrimination. Ultimately, reducing employers' and insurers' economic incentives for genetic discrimination is the key to successful prevention of this discrimination. We believe this can be achieved by enacting legislation that provides for guaranteed enrollment and uniform health insurance rate structures.

IEEE-USA recognizes that significant difficulties exist for proponents of comprehensive genetic nondiscrimination legislation. Perhaps as a result, the protections in the proposed legislation are narrow in scope -- limited to information regarding genetic tests and family histories, and not the diagnosis of genetic disease or drug/surgical therapies that treat the predisposition for genetic disease. We feel these omissions are problematic for two reasons: First, an individual is unlikely to undergo genetic testing if the proposed law *only* protects them from discrimination up until the point they might develop a genetically-linked condition. And second, the bill's definitions of "genetic information" and "genetic services" do not include preventative drug therapies and surgical interventions that might forestall such a diagnosis, thereby further discouraging proactive testing. Despite our concerns about the legislations limited scope, we support the bill as a meaningful first step. We believe a debate in Congress is critical to: 1) establishing the adequacy of the proposed legislation; and 2) educating the public on the extent of the protections included.

IEEE-USA's electrical and electronics engineers are at the forefront of health systems engineering and health informatics, areas that stand to benefit from increased utilization of genetic testing. As an organization, we believe that comprehensive genetic nondiscrimination legislation is vital to encouraging public adoption of the important opportunities that genetics offers in revolutionizing the quality of health care in our nation. Attached is our position statement, *Nondiscrimination in Employment Based on Genetic and Other Health Information*

(<http://www.ieeeusa.org/forum/POSITIONS/geneticinformation.html>), which provides our additional thoughts on the use of genetic and other health information.

IEEE-USA is an organizational unit of the IEEE. It was created in 1973 to advance the public good and promote the careers and public policy interests of the more than 220,000 technology professionals who are U.S. members of the IEEE. The IEEE is the world's largest technical professional society. For more information, go to <http://www.ieeeusa.org>. If we can be of further assistance, please contact Deborah Rudolph in our Washington office at (202) 785-0017 x 8332 or email at d.rudolph@ieee.org.

Sincerely,

A handwritten signature in cursive script that reads "Gerard A. Alphonse".

Gerard A. Alphonse
President, IEEE-USA

GAA/dr:bc

SAMPLE SENATE LETTER



21 April 2005

The Honorable Olympia Snowe
United States Senate
154 Russell Building
Washington, DC 20510

Dear Senator Snowe:

I am writing on behalf of The Institute of Electrical and Electronics Engineers-USA (IEEE-USA) and its Medical Technology Policy Committee to commend the Senate passage of S.306, the Genetic Information Nondiscrimination Act of 2005. Despite our concerns about S.306's limited scope, we support the bill as a meaningful first step and look forward to working with you toward final passage of this important legislation.

It is our position that the American public must be able to access the health benefits provided by genetic information without fear of consequent discrimination. Ultimately, reducing employers' and insurers' economic incentives for genetic discrimination is the key to successful prevention of this discrimination. We believe this can be achieved by enacting legislation that provides for guaranteed enrollment and uniform health insurance rate structures. Attached is our position statement, Nondiscrimination in Employment Based on Genetic and Other Health Information (<http://www.ieeeusa.org/forum/POSITIONS/geneticinformation.html>), which provides our additional thoughts on the use of genetic and other health information.

IEEE-USA recognizes that significant difficulties exist for proponents of comprehensive genetic nondiscrimination legislation. Perhaps as a result, the protections in S.306 are narrow in scope--limited to information regarding genetic tests and family histories, not the diagnosis of genetic disease or drug/surgical therapies that treat the predisposition for genetic disease. We feel these omissions are problematic for two reasons: first, an individual is unlikely to undergo genetic testing if the proposed law *only* protects them from discrimination up until the point they might develop a genetically-linked condition; and second, the bill's definitions of "genetic information" and "genetic services" does not include preventative drug therapies and surgical interventions that might forestall such a diagnosis, thereby further discouraging proactive testing.

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Sincerely,

A handwritten signature in black ink that reads "Gerard A. Alphonse". The signature is written in a cursive, flowing style.

Gerard A. Alphonse
President, IEEE-USA



POSITION

Nondiscrimination in Employment Based on Genetic and Other Health Information

**(Approved by the IEEE-USA
Board of Directors, 20 August 2002)**

IEEE-USA supports restricting the use of non-job-related genetic and other health information in employment decision-making, to discourage potential employment discrimination.

IEEE-USA recognizes that the American public needs to be able to embrace the increasing health benefits provided by genetic information without fear of consequent discrimination. Protection against such discrimination is essential for the adoption of new genetic technologies, the advancement of genetics research, and the realization of personalized medicine that improves outcomes and decreases suffering.

Electrical and electronics engineers are at the forefront of health systems engineering and health informatics. As such, they offer unique insight into the complex technical and legal paths that may allow sensitive health information to migrate beyond an individual's intent. Like all health consumers, engineers also stand to benefit from the accelerated arrival of personalized medicine. And like all employees, they have an interest in eliminating all forms of unfair discrimination in the workplace.

Presently, employers are able to obtain unrestricted access to an individual's health information by requiring that an applicant sign a general medical release following a conditional offer of employment. If the conditional offer is withdrawn, the individual usually has no legal right to an explanation of the reason for withdrawal.

Such an environment affords little protection against employment discrimination based on any sort of sensitive health information, particularly relating to one's genes. The current situation discourages the public from seeking out the benefits of genetic testing and impedes the widespread adoption of genetics technologies and the advancement of genetics research.

In response, IEEE-USA supports:

1. Restricting employers (including employment agencies acting on behalf of employers) from requiring, requesting, collecting, purchasing, or otherwise obtaining health information about an individual or the individual's family member(s), unless the requested information is:

a. directly related to the requirements of an individual's current or applied-for job position, or

b. necessary to support workplace health and safety monitoring, or

c. necessary for other health research activities for which, the employer will only receive aggregate data (not revealing the identity of individual employees).

Further, we recommend that employers must obtain voluntary written consent from employees or applicants who are requested to undergo medical tests and measurements. Prior to obtaining such written consent, the employer must provide:

i. purpose of the test or measurement;

ii. details of the analyses to be performed;

iii. applicable privacy policies and possible ramifications of the test results;

iv. details regarding the storage/destruction of test samples;

v. process for accessing test results and correcting errors in records; and

vi. proof of the testing program's compliance with applicable government regulations.

2. Restricting employers from making employment-related decisions based on health information, except in cases where that information is necessary to support workplace health and safety or to demonstrate an individual's ability to perform a specific job (e.g., meet minimum prerequisites for weight, height, and eyesight).

3. Adding safeguards against discrimination in employment decision-making where an individual's health information may be a contributing factor. In particular, employers should be required to inform an applicant in writing of the reasons for retracting a conditional offer of employment.

4. Minimizing the economic incentives that encourage employers to obtain non-job-related health information for use in their employment decision-making (e.g., restricting or eliminating the use of such information in the determination of group health insurance rates).

This statement was developed by the IEEE-USA's Medical Technology Policy Committee and represents the considered judgment of a group of U.S. IEEE members with expertise in the subject field. IEEE-USA is an organizational unit of The Institute of Electrical and Electronics Engineers, Inc., created in 1973 to promote the careers and public policy interests of the more than 235,000 electrical, electronics, computer and software engineers who are U.S. members of the IEEE.

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Staff Contact: Deborah Rudolph, d.rudolph@ieee.org

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