

Topic Updates: Genetic Discrimination

BY JEREMY GRUBER

First Public Case of Discrimination under GINA

In what appears to be the first publicly identified case of its kind, a Connecticut woman has accused her employer of violating the recently enacted federal Genetic Information Nondiscrimination Act (GINA).

With a family history of breast cancer, 39-year-old Pamela Fink and her two sisters took genetic tests at the Yale Cancer Center. The tests showed that all three carried the BRCA2 gene, predisposing them to breast cancer.

Both sisters developed breast cancer, but survived with treatment. After several biopsies and frightening false alarms, Fink opted for a preventative double mastectomy last year.

Feeling comfortable in what she described as a supportive work environment, she told her bosses at MXenergy about her genetic tests and the surgery, she said.

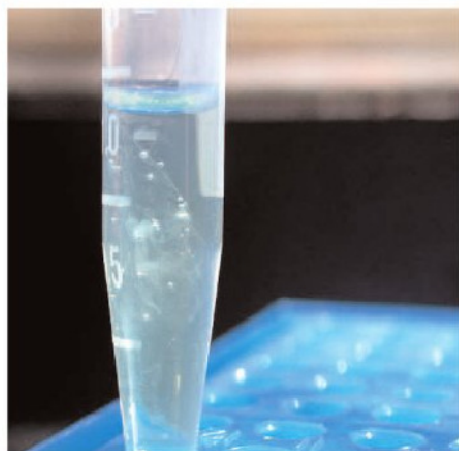
Fink alleges that, despite giving her “glowing evaluations for years,” her employer, MXenergy, soon thereafter “targeted, demoted and eventually dismissed her when she told them of the genetic test results.” MXenergy denies any wrongdoing.

GINA, which was passed by Congress in 2008 and took full effect late last year, represents the most comprehensive effort to date to regulate the use of genetic information by employers (Title II) and health care insurers (Title I) in the United States. Under Section 201(a)(i) of GINA, employers with more than 15 employees may not “discriminate against any employee with respect to the compensation, terms, conditions, or privileges of employment...because of genetic information.”

As with other civil rights laws, Title II requires that a complaint first be filed with the Equal Employment Opportunity Commission. Peggy R. Mastroianni, the

commission’s associate legal counsel, said most of the 80 complaints filed since the genetic law took effect seemed to involve cases in which employers had improperly acquired or disclosed genetic information. But Ms. Fink’s case alleges a more serious offense: an improper firing because of it.

How and if this case proceeds may shed light on how the EEOC and possibly the judiciary will begin to apply GINA. Regardless, it is an important reminder to employers and health insurers that GINA is now the law of the land.



Canada Considers Genetic Discrimination Law

Canadians need better protection from genetic discrimination by insurers and employers, according to Winnipeg North MP Judy Wasylycia-Leis. Mrs Wasylycia-Leis recently introduced Bill C-508, “An Act to amend the Canadian Human Rights Act,” in the Canadian House of Commons to prohibit discrimination on the grounds of a person’s “genetic characteristics.”

As other nations have begun to enact

such protections, supporters of the new bill claim Canada has fallen behind. Currently, Canada does have several laws protecting individuals from discrimination on the basis of disability. However, none of this legislation addresses the concepts of future disability, perceived disability or imputed disability. Nor does it prevent discrimination from taking place; rather, it offers remedies after discrimination has occurred. This puts the onus on the victim of discrimination to make the complaint and then seek appropriate legal action - a lengthy and expensive process.

Over the past two decades, various commissions and task forces have called for reform in Canada but none of their recommendations have been implemented. Meanwhile, the Canadian insurance industry’s position continues to be that if an individual has undergone genetic testing, insurers can request access to the results. Because Canada has a universal health care system, access to life, disability and critical care insurance - rather than health insurance - are the biggest issues at stake.

“This bill will stop Canadians’ personal genetic information from being used against them,” said Wasylycia-Leis in a press release preceding introduction. “Employers, insurance companies and others have already begun to discriminate against people based on their genetic make-up. People are being punished in fundamental ways—like being prevented from earning a living or buying a house—for something they have no control over. That’s unfair and this bill will update the Canadian Human Rights Act to deal with this 21st century problem.”

The Canadian Coalition for Genetic Fairness (CCGF) which was modeled after the Coalition for Genetic Fairness in the United States which led the successful effort to enact GINA, helped Mrs

Topic Update: DNA Databanks

The Texas Department of State Health Services sent 800 infant blood samples to the Army's forensic mtDNA database project - without parental consent

Wasylycia-Leis draft the bill. The CCGF wants regulatory reform for the insurance industry in light of genetic advances with particular attention on life, critical care, disability, and mortgage insurance.

Mr. Don Lamont, CEO of the Huntington Society of Canada and chair of the CCGF, says predictive testing is "a good thing," but warned it also carries "a growing fear that the information can lead to stigma and discrimination."

For more information on the Canadian Coalition for Genetic Fairness (CCGF) and how to support their efforts, you can visit their website at: www.ccgf-cceg.ca/en.

Jeremy Gruber, J.D., is President and Executive Director of the Council for Responsible Genetics.

The state of Texas has for years collected drops of blood from newborns in order to screen for birth defects. The baby's heel is pricked and five drops of blood are collected on a card, which is thrown out shortly after the screening.

Except when it isn't.

Without ever notifying parents, the Texas Department of State Health Services changed its policy in 2002. First it simply stopped discarding the blood samples after screening for birth defects. Then, with 800,000 samples coming in each year, the state began warehousing the cards at Texas A&M University. The DNA samples were ostensibly to be used for research purposes, but as *The Texas Tribune* reported earlier this year, 800 de-identified samples were also sent to be included in the creation of a national mtDNA foren-

sics database, a \$1.9 million project initiated by the Armed Forces DNA Identification Laboratory (AFDIL).

In research proposals dug up by the *Tribune*, the intention emerged to build an international mtDNA database to advance anti-terrorism investigations. While a large forensic DNA database already exists in the U.S., mtDNA is especially valuable, as it is easier to find and extract than nuclear DNA. AFDIL indicated that it was seeking anonymous mtDNA samples in order to increase the sample size of its budding database.

Scientists insist that mtDNA samples can be fully de-identified so that the sample can never be traced back to the individual who gave it; yet all parties involved in using the newborn samples for the AFDIL database—DSHS, AFDIL, and Texas A&M—neglected to make public note of the project, and in fact made specific efforts to keep it under the radar. DSHS emails revealed state officials' concerns that only bad publicity could come of press about the project, and the agency convinced Texas A&M to pull a press release announcing their partnership.

Researchers also made it clear that their work would go more smoothly if the DNA collection were kept under wraps. As the *Tribune* notes: "The problem ... is that scientists have used the public's unease with the subject as an excuse not to talk about it."

