

# Gene machine

**Not perfect? One day soon it might cost you your job.**

**The UK government has refused to rule out genetic testing at work. Hazards editor Rory O'Neill warns that as the gene test gadgets make genetic screening a wrong-headed but cheap choice for companies, we may find perfectly capable workers are discarded because of unsafe and unsound workplace gene tests.**

In the last five years, genetic testing has become an affordable option – unregulated, but used routinely by the police and increasingly common in our hospitals. UK transport companies are using DNA test kits to identify louts who spit at staff.

At work – where being at risk of an occupational disease isn't a crime or a personal trait, but the result of an exposure to an occupational risk – many, maybe most, UK employers are interested in a different use of genetic screening. They see a scientific shortcut that could weed out the weak and cut compensation and sick leave.

An Institute of Directors report in 2000 said 50 per cent of employers responding to a questionnaire thought it would be appropriate to conduct genetic testing "to see if employees are at risk of developing an occupation-related disease due to exposure in the workplace" and 34 per cent thought it would be appropriate "to see if they will develop heart disease which might affect sickness or early retirement."

The response from union, equality, health and disability organisations has been far less positive.

## Screen test

In October 2003, ETUC – Europe's top union body – called for the European Commission to ban genetic screening across the European Union (page 5).

And in September 2003, TUC teamed up with GeneWatch UK and the British Council of Disabled People (BCODP) to call on the UK government to outlaw genetic discrimination at work.

A GeneWatch report, *Genetic testing in the workplace*, revealed that genetic tests cannot accurately predict which workers will suffer future disability or illness.

Despite this, employers want to use genetic tests and many research projects are seeking to identify those "genetically susceptible" to workplace hazards, the report said.

"Some employers might see selecting workers on the basis of genetic tests simply as a more economic and efficient means of employee selection," it said.

TUC general secretary Brendan Barber said: "We want the government to make sure everyone has an equal right to succeed at work, whatever their genetic inheritance. We should be promoting opportunities for all, not penalising people because of their genes."

In January 2002 TUC's own report, *Ban unfair screening*, said "we oppose susceptibility screening as this will remove the emphasis on an employer's legal duties to make the workplace safe for all."

The June 2003 government White Paper on genetics in the NHS, however, made no commitment to legislation to prevent genetic discrimination. Instead, the government has opted for a "moratorium," a watching brief that leaves hope for the biotech, business and insurance industry lobby and their gene test plans.

## Genetic flaws

The GeneWatch report warns that policies to winnow out the weak or the susceptible are "fundamentally flawed."

The report says: "Genetic tests could result in many – perhaps hundreds – of workers being excluded to prevent one case of a workplace-related disease. The majority of those excluded would suffer the ill-effects of unemployment on their health and finances, even though they might not actually belong to a higher risk group." The report argues:

- ◆ There are more effective ways of improving employees' health – for example, meeting legal duties and ensuring risks are "eliminated,

## Not working

**In 2001, Hazards warned of serious dangers in the use of genetic screening at work (Hazards 74).**

**It doesn't protect workers – occupational and environmental factors are a far more productive focus of preventive action.**

**It does protect hazards – genetic screening tended to give some, often dubious, protection from one risk. But many targeted substances including benzene, beryllium, lead and cadmium have many more and more serious risks for the entire workforce that would have been a better target for "preventive" efforts.**

**It is discriminatory – gene markers chosen are sometimes linked to race or gender.**

**Gene tests have never had the approval of the UK safety establishment. A 1995 Health and Safety Commission working group concluded genetic science was not a reliable and accurate predictor of a predisposition to occupational ill health.**

reduced or, at the very least, effectively controlled."

- ◆ The imbalance of power between employer and employee makes it difficult to ensure an employee is giving their voluntary consent to a genetic test – job applicants could face discrimination and existing workers might not be able to walk away from a high risk job, but could have the test used against them if they didn't leave the job and went on to develop an occupational disease.
- ◆ A genetic test could have wider implications – for blood relatives, or when applying for other jobs or for insurance.
- ◆ The tests are unethical – excluding people from employment on the basis of their genetic make up is a violation of their fundamental human rights (*Hazards 72*).
- ◆ Tests are complex and open to misinterpretation, can lead to "false positive" results, and to a generally unemployable "genetic underclass."

For those with something to gain – the plethora of firms flogging testing kits for example, or the employers looking for a cut price alternative to safe work – the your-money-or-your-life argument might have its attractions.

For workers, a safe workplace would be a far healthier option.

## Tests fail the test

GeneWatch argues that your genetic fingerprint is personal, and not personnel, information.

This argument appears to be winning favour in the US where, despite support of a powerful business and biotech lobby, genetic screening's days could be numbered.

In October 2003 the Senate voted by an overwhelming majority to approve legislation that would prohibit companies from using genetic test results to make employment decisions, deny health coverage or raise insurance premiums.

Employers would be barred from seeking most genetic information, and from using any such information to influence hiring or promotion decisions.

Employers could, however, require testing to monitor potential ill effects from workplace exposure to hazardous substances. And workers' advocates warn that the proposed US law has employer-friendly loopholes – it would not, for example, rule out gene tests in occupational disease compensation cases, so the gene testers could still have a route into the workplace.

Testing can be a costly mistake for employers, however. In 2002, the US Equal Employment Opportunity Commission (EEOC) told Burlington Northern Santa Fe Railroad that its secret genetic testing of some employees violated disability laws (*Hazards 74*).

An EEOC official said Burlington Northern broke the Americans with Disabilities Act by performing genetic tests on workers with carpal tunnel

syndrome and then discriminating against them, and should pay substantial compensation.

In December 2000, a US federal court approved a \$2.2 billion settlement to thousands of employees of Lawrence Berkeley Laboratories who had been secretly tested for decades for syphilis, pregnancy and the genetic trait for sickle cell disease.

## Predictable response

Elsewhere, developments have given the gene test lobby more reason to be cheerful, despite informed union opposition.

In its January 2002 submission to an official Australian Law Reform Commission (ALRC) enquiry, union federation ACTU echoed TUC's call for a ban on gene testing at work, adding "the focus in workplace health and safety needs to be on hazard removal, not on a mathematical calculation of risk based on genetic testing."

In May 2003, the ALRC report, *Essentially yours: The protection of human genetic information in Australia*, concluded however that "it is not appropriate to impose a complete prohibition on the use of genetic information by employers to screen for work-related susceptibilities."

The ALRC rationale is straight out of the employer-insurer-biotech play book.

An accompanying ALRC news release concluded "the arguments in favour of genetic screening for work-related susceptibilities include its potential to protect susceptible employees from avoidable risk to their health and safety, and to protect employers from potential legal liability and financial costs for illness suffered by susceptible employees."

It says that gene screening should "generally" be conducted only on a voluntary basis, but adds in certain circumstances "it may be reasonable to implement a mandatory screening programme."

Findings like this will give the biotech companies hope there is a market out there for the test kits, and will give employers a glimmer of hope that they will be able to reduce their risks *without reducing the risks at work*. It is a dangerous development.

For you – it is your body, your genes, your future. When the boss sends in the gene testers, remember it may be their company, but your genetic fingerprint is your business.

## References

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