

No more working weak?

In February 2001, scientists announced they had mapped out the entire human genetic code. Medics were elated, predicting remedies for deadly diseases; the press latched onto every promise of "golden bullets" and "miracle cures". The news was less rosy for the workforce, though, as employers and insurers saw an opportunity to winnow out the weak or susceptible from the workplace.

The Burlington Northern Santa Fe railroad secretly performed genetic tests on the blood of workers with carpal tunnel syndrome, a common work-related condition. The screening programme only came to light after the company's workers complained to their union.

Harry Zanville, an attorney for the union, claims that 125 workers recently gave blood samples and that at least 18 were subjected to gene tests without the employees' consent.

The reason? Money, says Zanville, who claims the company hopes to avoid paying out millions to workers who develop the painful musculoskeletal disorder at work. The condition is one of the top work-related health problems.

Separate court cases brought by four union members who charged the company with discrimination, and by the Equal Employment Opportunities Commission, the organisation policing the Americans with Disabilities Act, quickly

brought an end to the covert testing, within days of the union exposing the practice.

Geneticists themselves have questioned the legitimacy of the carpal tunnel test. They point out that the disease is a common workplace disability, and the "chromosome 17 deletion" looked for in the gene tests is extremely rare.

"I'm a humanist physician. I try hard to make the world a better place," said Phillip Chance, the geneticist at the University of Washington in Seattle who discovered one of the mutations, in a 19 February *US News* interview. "This would be the last thing I'd want to see happen with my work."

Still, the Santa Fe screening is not an isolated case. Last December a US federal court approved a \$2.2 billion settlement to thousands of employees in a case involving the genetic privacy rights of workers at Lawrence Berkeley Laboratory.

LBL workers for decades were tested secretly and illegally for syphilis, pregnancy, and the genetic trait for sickle cell disease. The then

president Bill Clinton last year banned genetic discrimination against federal employees, but the rule was not extended to the private sector.

The use of workplace gene tests in the US is already on the increase. In 1982 a US federal government survey found 1.6 per cent of companies responding were using genetic tests for employment purposes. In a similar 1997 survey by the American Management Association, 6-10 per cent of employers were found to be conducting genetic screening.

A Genetic discrimination

in the workplace factsheet from the American Civil Liberties Union (ACLU) cites a 1997 US government report that "found genetic information to be a very serious workplace issue."

In a March 2001 response to a UK Human Genetics Commission discussion document, the TUC warns of the perils of following the US path.

TUC's submission to the Commission, the UK government's independent advisory body on human genetics, says there is "a real danger that a similar pattern will emerge with genetic testing for employment pur-

Testing our patience

There are serious dangers in the use of genetic screening at work.

IT NEVER WORKED: Attempts in the 1960s to introduce workplace genetic screening were soundly rejected because occupational and environmental factors were a far more productive focus of preventive action;

IT STILL DOESN'T WORK: Efforts over 30 years to push gene screens for sensitivity to the potent workplace asthma cause TDI and other substances have failed (*Asthma at work: Causes, effects and what to do about them*. TUC, 1995);

IT MISSES THE POINT: Genetic screening tended to give some – often dubious – protection from one risk. Many targeted substances including benzene, lead and cadmium have many more and more serious risks for the entire workforce that would be a better focus for "preventive" efforts; and

IT IS DISCRIMINATORY: The markers chosen are often linked to race – Sickle cell, Tay Sachs, Glucose-6-phosphate dehydrogenase (G-6-PD) deficiency – or gender which could have lead to something uncomfortably close to workplace eugenics. One paper estimates that 12 per cent of African Americans would have been excluded from jobs in the chemical industry if an exclusion of people with sickle cell trait was introduced.

Without exposure to hazards, we can all work safely, regardless of our alleged genetic foibles, says the TUC.



Graphic: Marzenna Beata Musial/CIOP Poland



poses as it becomes cheaper and more readily available, and as multinational companies with UK premises introduce such screening. Strict controls should be put in place before this happens rather than afterwards."

Genetic screening is still rare in the UK. Air force pilots are tested for the traits for sickle cell anaemia and scene-of-crime officers in the police force have their genetic fingerprint held on record to eliminate them from enquiries where their genetic material may have contaminated evidence.

TUC objections to genetic testing for employment purposes are based on three considerations:

- ◆ Many people who test positive for genetic muta-

tions associated with certain conditions will never develop those conditions. Excluding or removing people from the workplace just because they might develop a genetic condition is unacceptable;

- ◆ genetic screening offers a false option in terms of controlling workplace risks. These risks should be controlled for everyone, rather than selecting a workforce less likely to suffer the results of those risks; and

- ◆ screening purely on grounds of cost benefit analysis is not acceptable – economic considerations cannot excuse something which is morally wrong.

The boost given to genetic testing by the completion of the human gene map could encourage interest in this type of screening as a cheap and easy replacement for good health and safety management standards in the workplace, or as a way to limit insurance liability.

Employers' liability insurance is one of the UK insurance industry's least

profitable ventures, and the industry is keen to limit its costs.

UK unions think the best way to do that is to reduce the risks faced by workers. "First and foremost employers must provide a safe working environment," says TUC. "For example, they have a specific legal duty to eliminate hazardous chemicals in the workplaces and find safer substitutes. This type of genetic screening is about eliminating the worker rather than the hazard which is simply unacceptable."

TUC says it "is aware of one employer who approached the HSE to ask whether, if there was evidence that some people were genetically predisposed not to suffer the effects of certain hazards, they should be preferred in employment likely to create exposure to that hazard."

The TUC submission concludes: "Workers are hired to do a job and should be protected so long as they meet the job's requirements. They should not be subjected to employers 'guessing' how their health may or may not change in the future."

Whose hands on your genes? A discussion document on the storage, protection and use of personal genetic information. Human Genetics Commission, November 2000. Free from: PO Box 777, London SE1 6XH. Available online at: www.hgc.gov.uk/

Ban unfair screening: The TUC's response to Whose hands on your genes? 20 March 2001. www.tuc.org.uk/h_and_s/
Genetic discrimination in the workplace factsheet. ACLU. www.aclu.org/issues/worker/gdfactsheet.html

Screening out discrimination

The TUC wants strict genetic screening safeguards to protect workers from unscrupulous, discriminating employers. In its March 2001 submission to the Human Genetics Commission, TUC said:

- ◆ We oppose susceptibility screening as this will remove the emphasis on an employer's legal duties to make the workplace safe for all.
- ◆ We would like to see an amendment to the Disability Discrimination Act 1995 to include asymptomatic (symptom-free) employees, or prospective employees, who have tested positive to a genetic mutation. Pre-employment screening may be appropriate in rare occasions but employers carrying out such tests should still be subject to the Disability Discrimination Act 1995.
- ◆ Employers should be prohibited from using genetic information to affect the terms, conditions, privileges, and benefits of employment.
- ◆ An individual should never be forced to take a genetic test for employment purposes and an individual's right to know their genetic constitution, privately, should be upheld.
- ◆ In rare cases where tests are implemented there must be informed and written consent. People being tested must be counselled by a competent individual and have access to support from a third party such as their union. Occupational health staff should not be classed as competent unless they have undergone specific training in this area. Workers' representatives must be consulted on the introduction of any such testing.
- ◆ Medical records of genetic tests must be treated with utmost confidentiality. They should not be the property of the employer and should not be released to any third party, for example insurers, without the employee's consent. General consent to release medical records should not include genetic screening records.
- ◆ We would like to see the situation regarding genetic screening and employment subject to regular review by the Government, in consultation with stakeholders including the TUC. Ideally, responsibility for this should rest with the Health and Safety Commission.