

# A scarlet letter or a red herring?

Genetic discrimination is of little concern compared with existing US healthcare problems.

*Sir*— A news magazine recently reported on a study published in the *New England Journal of Medicine*<sup>1</sup> showing that a particular combination of common genetic polymorphisms at two different loci increases the risk of congestive heart failure. The writer noted that genetic testing should be helpful in identifying individuals who might benefit from preventive measures, but also lamented that “until we have better safeguards against genetic discrimination by employers and insurers, routine screening is unlikely.”<sup>2</sup> Blanket assertions of this sort continue to appear in the general media as well as in the peer-reviewed scientific literature<sup>3</sup>, despite abundant evidence that such discrimination is exceedingly rare, if it occurs at all<sup>4</sup>.

Hall and Rich<sup>5</sup> and others have amply documented the fact that, for primarily economic reasons, health insurers are not inclined to discriminate on the sole basis of a theoretical risk of future disease. In contrast, an individual who already has a serious illness presents the insurer with an altogether different magnitude of risk, because costly claims are almost inevitable. If an applicant for individually underwritten health insurance is worried about discrimination, it makes more sense to fear a mammogram,

for example, than being tested for a *BRCA* mutation, because tests that detect actual disease are vastly more likely to trigger an adverse underwriting decision. Genetic discrimination in life insurance is also, for sound economic reasons, unlikely to become a significant social problem<sup>4</sup>.

Employers, too, have a financial interest in the current health of present and potential employees. But, here again, examples of genetic discrimination are few. A notable exception seems to be a well-publicized case involving the Burlington Northern Santa Fe Railroad<sup>3</sup> in which up to 20 workers who claimed that their jobs gave them carpal tunnel syndrome were unknowingly tested for an obscure genetic marker that the railroad hoped might establish that the problem actually represented a pre-existing (rather than occupational) condition. Although this testing may have been stunningly ill advised, it is remarkable that, when the case is cited as an egregious example of genetic discrimination, it is not mentioned that these workers already had the condition for which the testing was performed.

Genetic discrimination is, according to one definition, “discrimination against an individual or against members of that individual’s family solely because of real or

perceived differences from the ‘normal’ genome of that individual.”<sup>6</sup> The concept of genetic discrimination becomes meaningless once the definition is broadened to include actions against individuals who already manifest a disease, and yet the fear of such discrimination continues to be validated and perpetuated by the scientific establishment and the media.

Objective examination of the genetic-discrimination issue instead highlights intractable problems in other areas of public policy, notably the need for a universal system of healthcare funding in the United States. Although gene-based medicine will ultimately succeed or fail on its merits, public acceptance of the technology in the near future will hinge on the ability of the medical and research communities to demystify the technology and put the risks and benefits into perspective.

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2. *Newsweek* **74**, 21 October (2002).
3. Rothenberg, K. H., & Terry, S. F. *Science* **297**, 196–197 (2002).
4. Nowlan, W. *Science* **297**, 195–196 (2002).
5. Hall, M. A. & Rich, S. S. *Am. J. Hum. Genet.* **66**, 293–307 (2000).
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## Travel grants available for genetics congress

*Sir*— Many geneticists are planning to attend the 19th International Congress of Genetics, to be held in Melbourne on 6–11 July 2003. Because 2003 is the fiftieth anniversary of the publication in *Nature* of the seminal paper by Watson and Crick on the DNA double helix (J. D. Watson and F. H. C. Crick, *Nature* **171**, 737–738; 1953), the congress represents a timely vantage point from which to celebrate the advanced state of the art of genetics, to reflect on half a century of its successes and failures, and to debate its future.

International genetics congresses are significant, inspiring occasions for geneticists from developing countries, providing them with a rare opportunity to meet the top international researchers. Hence, the International Genetics Federation (the official congress sponsor), together with the Australian organizers, has financed some travel bursaries to be awarded on a competitive basis to needy geneticists, especially those from developing nations. Application details can be found on the Congress website at

[www.geneticscongress2003.com/index.php](http://www.geneticscongress2003.com/index.php).

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## Spiritual link is part of traditional knowledge

*Sir*— In presenting traditional knowledge as a commodity, your News story “Tribes query motives of knowledge databases” (*Nature* **419**, 866; 2002) fails to emphasize the spiritual connection between indigenous peoples and Mother Earth. The use of traditional knowledge must reflect the values that are the foundation of the elders’ practices, especially with regard to medicine. This principle must drive any discussion of how to document such knowledge.

The Centre for Traditional Knowledge understands this and is not asking aboriginal groups to make available their databases as implied in your story. Traditional knowledge should be documented in this way only if the communities themselves choose to do so on their own initiative. Our

organization — not part of the Canadian Museum of Nature, though strongly supported by it through shared facilities and access to scientific expertise — is working only to create a database of expert practitioners and their expertise. We have nearly completed a needs assessment to see how to document their names and expertise in a useful and respectful manner.

Many industries, and governmental and aboriginal organizations, would benefit by identifying the expertise of elders through the use of a database. But only those who know how to work with the spirit world and the medicines will determine what, if anything, can be sold. It is hard to imagine a profit-based venture forming a good relationship with a medicinal plant. Practitioners know that respecting the plant is often essential to the efficacy of the medicine, which is not a miracle chemical compound but a measure of curative energy that draws its medicinal qualities from the relationship between the plant and the people or the person. And you can’t buy a person’s power.

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