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Keep an eye on genetic screening

The potential abuses of genetic screening should not be exaggerated, but neither should they be ignored. Governments must ensure that private screening services operate responsibly. Careful oversight, even in a climate of deregulation, is essential.

ONE of the most striking aspects of modern genetics is the way in which the public controversies it generates rapidly become a reflection of broader concerns, in the process magnifying these concerns into caricature. This has long been the case with the ethics of genetic engineering itself, whose goals are frequently reduced — in the public's mind at least — to images of Frankenstein-like monsters. It is also a danger in current debates about the responsible use of genetic testing.

The issues involved are far from straightforward, ranging from the statistical uncertainty of the science of genome analysis, through the highly personal evaluation of risk, to difficult choices about the appropriate forms of medical intervention. For example, the genetic mutations associated with breast cancer — to take the most recent example of what is likely to be an increasing list of polygenic diseases for which screening becomes available — can create enormous complexities. Even where a mutation can be identified, translating this into information about the susceptibility of an individual to the disease can be daunting, given the other factors involved. So, too, can the choice of preventive measures, none of which has been shown to be fully effective.

The debate becomes even more complex when commercial factors come into play. Last month, for example, Myriad Genetics Inc. of Salt Lake City, Utah, announced that it was offering to carry out comprehensive sequence analysis of the recently discovered *BRCA1* and *BRCA2* genes for susceptibility to breast and ovarian cancer. The cost of the test is $2,400, with $395 for each additional member of an at-risk family once a mutation has been identified. For some individuals, particularly those with a family history of breast cancer, or coming from a social group (such as the Ashkenazi Jews) in which mutations in either gene are particularly prevalent, the test may well be worth the price. For others, the balance may be more difficult to judge, for example when the uncertainty created by the result of a screening test is no less worrying than the uncertainty caused by a lack of knowledge.

It is obviously essential that the information and advice given to women about whether to take the test, and how to interpret its results, are handled sensitively. Myriad has, to its credit, shown itself aware of this responsibility. For example, it has set up a scheme with the Dana-Farber Cancer Institute in Boston to provide a confidential registry of women who have been tested for *BRCA1* and *BRCA2* mutations, and has worked with genetic counsellors to draw up a national directory of counselling resources.

At the same time, however, there has been an almost messianic quality in the public statements of some of Myriad's senior scientists about the extent to which genetic screening is opening up a new world of medicine, in which the treatment of disease will be replaced by prevention — a distant and uncertain prospect than runs the risk of raising false hopes. And there is always a concern that the promise of fat dividends for shareholders is a major driving force behind any company's involvement in the health field.

What should the US government do? This issue is currently being examined by a joint working group established by the National Institutes of Health and the Department of Energy (see page 101). Some members of the working group are keen for the Food and Drug Administration (FDA) take on a regulatory role in ensuring that genetic screening is handled responsibly by private companies. Others, particularly those associated the companies themselves, warn that zealous regulation is unnecessary, and will only increase costs.

The FDA has made clear its reluctance to take on this role. Its main argument is understandable — if morally questionable — namely that it lacks the resources to do the task properly, at least not without cutting its commitment to other tasks. But it would be a disgrace if an issue as important as the proper use of genetic testing was reduced to a struggle over money. Countries such as Britain, as committed as the United States to the principle of deregulation, have nevertheless acknowledged that there are areas in which more government-backed supervision, not less, is appropriate. Genetic screening is one of these areas, and the US working group should have the political courage to acknowledge it. □

Eurovision for science?

A newly conceived association for science and society in Europe deserves antenatal support.

RAISING the public profile of science, providing a forum for open debate about its impact on society, and helping to promote the professional interests of scientists in general: such are the purposes of the American Association for the Advancement of Science and equivalent bodies elsewhere. The aims are grandiose, and the organizations' achievements inevitably fall short of the visions of their founders. But media coverage of their annual meetings is sufficient to suggest that they continue to play a significant role.

Europe lacks an organization with such ambitions on a pan-European scale, whether within the member states of the European Union or more broadly. It has transregional bodies that represent the interests of élite academics, the heads of funding agencies, individual scientific disciplines, and more. But an open association, intended to include both natural and social scientists, as well as others with a direct interest in the sciences, should — with a well-publicized debate here or a critical report there — have a complementary role to play. Certainly, public debates at the national level within Europe about science-related issues of multinational dimensions are too often blinkered by a lack of appreciation of the interests and instincts of other countries.

For those reasons, *Nature* welcomes the fact that a body called Euroscience, which is intended to help fill that gap, is now being formed. The appearance of the first announcement to that effect in our pages (page 108) reflects that welcome. (There is no other link between 'Euroscience' and this publication.) The new organization will face many obstacles, Europe being the diverse, contentious and politically heterogeneous region that it is. And Euroscience has yet to take effective action to meet its vision.

But it is easy to snipe at visionaries. Better to give support at this embryonic stage to ensure that Euroscience's agenda is practicable, its goals clearly defined and attainable, and its targets likely to achieve maximum impact. Each is essential if the association is to be helped over its next practical hurdle: attaining financial support, and thus a clout that goodwill alone cannot provide. □