

Genetic diversity proposal fails to impress international ethics panel

Paris. A multimillion-dollar project to study genetic variation in populations worldwide — the Human Genome Diversity Project (HGD) — appears unlikely to receive the endorsement it has been seeking from the United Nations Educational Scientific and Cultural Organization (Unesco).

The project — in which DNA would be collected from around 25 individuals from about 500 of the 5,000 or so different ethnic groups — is the brainchild of Luigi Luca Cavalli-Sforza, a renowned population geneticist at Stanford University in California. Knowledge of the origins of populations would have “enormous potential for illuminating our understanding of human history and identity”, and provide information on the genetic basis of predisposition and resistance to disease.

The project, which it is estimated would cost around \$5 million annually, has been backed by the Human Genome Organization (HUGO). But it has obtained little funding, partly because of controversy about its procedures and implications. Its supporters have been lobbying Unesco to set up an ethics committee to oversee the project, in a bid to improve HGD's image and to increase its prospects for funding.

But at a meeting of Unesco's International Bioethics Committee (IBC) in Paris last week, a working group on population genetics set up by the committee strongly criticized the HGD, and recommended UN organizations not to endorse any individual project in this area in order to “safeguard” Unesco's “independence, neutrality and credibility”. One Unesco official also says it rejected a separate request from HDG for direct funding.

The working group acknowledged the

Medical charities win lottery funds

London. Britain's medical research charities could receive up to £50 million (US\$80 million) next year from the proceeds of the recently-launched national lottery, following complaints over their exclusion from the first round of charitable grants, due to be made later this month.

Many medical charities, particularly the relatively smaller ones which lack large legacies, say that they have suffered a significant drop in income since the lottery was launched. In announcing that the first distribution of grants next year will concentrate on health, disability and care, the National Lottery Charities Board is hoping to temper some of this criticism. □

validity of the project's scientific goals. But it also endorsed criticisms by indigenous peoples, the main target of HGD. The group said, for example, that the project needs to clarify how — if at all — intellectual property rights would be claimed on biological material derived from populations.

Indigenous groups are angry that the US Department of Commerce has filed patent

Debra Harry, a Paiute North American Indian who works with the Indigenous People's Biodiversity Network, said that genetic research is “not a priority for indigenous peoples”. She pointed out that basic human rights, such as access to better health care, are a better guarantee of their well-being and survival, and added: “They've come to take our blood and tissues for their interests, not for ours.”

Harry invoked the 1964 Helsinki Declaration — “in research on man, the well-being of the subject takes precedence over science and society” — to argue for a halt to HGD on the grounds that indigenous peoples feel they will not benefit from it. Indeed, she claimed that information from HGD would in fact increase discrimination against indigenous peoples.

Cavalli-Sforza has argued that HGD would reduce the risk of racism by showing that the notion of race is flawed. But the IBC group described this as the “most debatable” claim of the project, arguing that the prejudice that gives rise to racist and eugenic attitudes tends to pervert scientific results to its own ends. Genetic reductionism, argued many at the meeting, represents a threat to those mythologies of human origins that are different from those of the dominant world cultures.

Moreover, the working group argues that opposition is based upon more than misunderstandings of the scientific aims or anti-science attitudes, but “is a clash of philosophy and cultural insight”. Harry, for example, says that “genetics is a violation of our ethics, it attacks our culture's world view”. She adds: “We don't view our genes as protein actions ready to be interpreted; for us our genes are sacred.”

One ethnological researcher at the meeting urged biologists to learn to “respect community rights”, adding that their discipline has become accustomed to working under enormous constraints. These include lengthy approval procedures, and making notes available to the groups being studied.

Cavalli-Sforza, who attended last week's meeting, said he welcomed the committee's analysis, and “shared their concerns”. HGD, he added, was drafting protocols that would go “even further” than the committee's recommendations.

But he dismissed the claims concerning the project's risks as “exaggerated”, and continued to attribute them to misunderstanding. “I have become used to being called a planner of genocide and of being accused of economic interest,” he says. “My main aim is to defend the project and defend science.”

Declan Butler

IMAGE
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REASONS

Natural rites: genome data 'could threaten traditional beliefs' of indigenous peoples.

claims on cell lines taken from indigenous people from the Solomon Islands. The islands' government has protested. But Ron Brown, the US Secretary of Commerce, replied last year that the origin of cells was irrelevant to the patent application.

The working group also asked HGD, which is managed by a subcommittee of HUGO, to “formulate concretely” its general claims that the project would benefit local populations. HGD's claim that it will lead to the development of local research laboratories, for example, needs to be clarified so that “it becomes obvious how this would happen”. The working group also wants confirmation that HGD would not seek commercial funding, despite its fragile financial situation, and called on HGD to include indigenous peoples in all stages of the project.

The long list of criticisms reflects a general feeling at the meeting that the enthusiasm of the project's supporters for scientific results has led to the neglect of wider issues, in particular human rights. The working group pointed out that although HGD has “expressed urgency” in collecting samples from peoples in danger of cultural and physical extinction, it had not expressed concern about their extinction *per se*.

Indeed, speaking at last week's meeting,

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