

# Indian researchers press for stricter rules to regulate 'gene-hunting'

**New Delhi.** The Indian government is coming under pressure from some of its own scientists to tighten the rules on the export of human DNA and blood samples. This follows growing evidence of the interest of foreign research groups in using India as a fruitful 'hunting-ground' for disease genes and their mutations.

Much of the pressure is coming from Indian researchers concerned that some valuable genetic information appears to be being taken from the country 'illegally' under the guise of collaborative research in human genetics.

Since 1992, the export of biological tissues has required specific clearance from the Indian Council of Medical Research (ICMR). But the council lacks sufficient powers to enforce the rule, and its officials say that they therefore feel unable to do anything about samples leaving India without their knowledge (see box below).

With its huge population of diverse cultures and significant in-breeding, India is a natural setting to look for rare genetic mutations. The Onge tribes of India, for example, have a small Y chromosome and low sperm

count, while a community of 700 families in southern India suffers from a combination of osteoarthritis and dwarfism.

"Name any genetic disorder and we have the mutations," says Samir Brahmachari, professor of molecular biophysics at the Indian Institute of Science in Bangalore. "If you are looking for twins, we have plenty."

India also provides scope for "differential genome comparison". In West Bengal, for instance, where cholera is endemic, a large group of individuals appears to be immune to the disease. The gene responsible, which may eventually lead to a valuable commercial product, is now being sought at a laboratory in Calcutta using sophisticated equipment donated without strings by the government of Japan.

In addition, Indian geneticists point out that, with family structures crumbling in the West, the data about large families required for linkage studies are available only in India because China — the other populous country — is not easily accessible.

IMAGE  
UNAVAILABLE  
FOR COPYRIGHT  
REASONS

Roderick Johnson/Panos

**Family affairs: the incidence of large families and in-breeding makes India attractive to geneticists.**

But the growing interest of foreign research groups is prompting the Department of Biotechnology (DBT) to tighten rules on the export of genetic data, and to draw up guidelines for international collaboration before the launch of the Human Genome Diversity Project (HGDP), a global effort to study genetic variations in *Homo sapiens* (see *Nature* 377, 372; 1995).

The latter project is planning to study blood samples taken from indigenous populations worldwide, including 23 ethnic ►

## Scientists challenged over 'unauthorized' export of data

**New Delhi & Washington.** Researchers from the US National Institutes of Health (NIH) have been accused of violating an Indian government regulation forbidding the export of biological material without specific permission from the Indian Council of Medical Research (ICMR).

According to a spokesman for the ICMR, the NIH's National Eye Institute (NEI), which is collecting DNA and blood samples from patients at major private eye hospitals in India, has not obtained the authorization required to take samples out of the country, and is therefore acting "illegally".

But Carl Kupfer, the director of the NEI, while confirming that the institute is receiving blood samples from India, points out that the research protocols have been cleared by review boards in both India and the United States. He adds that neither the NEI, nor the Indian hospital with which it is collaborating, is aware of any requirement to clear the arrangement with the ICMR.

The US scientists are searching for the gene or genes that cause retinitis

pigmentosa (RP), otherwise known as night blindness. India is an ideal social setting for mapping the location of the gene because of its large families — several members of which can suffer from RP — and the high incidence of intermarriage.

The NEI is already collecting samples from L. V. Prasad (LVP) Eye Hospital in Hyderabad, and is engaged in discussions to collect similar samples from three others, the Sankar Nethralaya in Madras, Little Flower Medical Centre in Angamally in Kerala, and an eye hospital in Amritsar. The last of these has a large database with details of more than 20,000 patients suffering from RP and congenital cataract.

According to Subadra Jalali, a surgeon at the LVP hospital, blood samples of 80 members belonging to six RP-affected families have already been sent to the NIH, and the hospital has agreed to provide such data on 20 families over a period of three years. In return, says Jalali, the NIH will provide the hospital with \$180,000 to cover payments to patients who give blood

"voluntarily".

Government officials claim that NIH is not the only foreign body which, they say, is exporting without authorization Indian blood samples. Researchers at the Duke University Medical Centre in Durham, North Carolina, for example, are close to identifying the mutation responsible for juvenile myoclonic epilepsy (JME) which accounts for ten per cent of all epilepsies.

The US scientists were fortunate to find a clinician in a Delhi hospital who provided them with blood samples from what is said to be the world's largest family with JME. Nine of its 30 members are affected.

In response to the charge that US researchers are bypassing the views of leading Indian geneticists and ignoring local export regulations, Kupfer points out that the NEI project is being carried out in collaboration with J. S. Murty of the University of Osmania at Hyderabad, a past-president of the Indian Society of Human Genetics, and that it includes a strong training component.

**K. S. Jayaraman and Colin Macilwain**