who shared the same mother but had different fathers.

Extensive cytogenetic investigations by Wahlstrom in Sweden raised initial hopes of an association with a fragile site at Xp21, but this has not been confirmed by further analyses. With increasing awareness of the clinical features of this neurodegenerative syndrome many more cases are likely to be diagnosed in the near future, and hopefully the enigma of its origin and sex preference may be unravelled.

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Ethical practices
Two recent meetings have highlighted some of the ethical issues which are important to both the 'old' and the 'new' genetics.

At the International Congress of Human Genetics, one of the best organised sessions was the symposium 'Ethical and legal issues in applied human genetics' chaired by the peripatetic ethicist, John C Fletcher (NIH). Good clear presentations, kept strictly to time, allowed full discussion and made a welcome relief at a congress notable for its vast numbers and prolixity. The workshop was opened by Fletcher and his colleague Dorothy Wertz, who described a crosscultural study begun in 1984. Four 'dominant moral approaches' may, according to Fletcher, be evolving as shown by the results of a survey: 643 medical geneticists from 17 countries replied from the 1020 sent the questionnaire. The four 'dominant moral approaches' are (1) parental (that is, consultand) autonomy; (2) the obligation to reduce or prevent the suffering caused by genetic disease on the condition that parental autonomy is respected; (3) a duty to provide full disclosure of test results (including colleague disagreements); and (4) a voluntary rather than mandatory approach to genetic screening except for newborns when treatment is available. The ethical principles which appear to be widely accepted across all countries are Autonomy, Beneficence, Non-maleficence, and Justice (or equity).

Of the specific problems put to medical geneticists in the questionnaire, those that created greatest ethical conflict included confidentiality of a diagnosis of Huntington's chorea versus duties to relatives at risk, disclosure of an XY genotype in a female, and prenatal diagnosis for sex selection (with no X-linked disease involved). It was fascinating in the discussion to hear that the practice in Canada was to reject the use of prenatal diagnosis for sex selection, although it had appeared from the questionnaire returns that a majority in Canada (and the United States and Hungary) would either perform it or refer to someone else who might. According to Fletcher, individual medical geneticists would admit views in an anonymous questionnaire which they would not implement or even disclose in public. It also emerged that the private sector might be a factor in the development of such fringe activities in North America. In other cultures sex selection is anything but 'fringe', but these views were not discussed. (Reprints of the full paper can be obtained from Dr Fletcher, Holding 10, Room 2C-202 NIH Bethesda, Maryland 20892, USA.)

Bernard Dickens (Toronto) followed Fletcher by discussing 'Comparative law and legislation on eugenic sterilisation and selective abortion'. This was a valuable summary of present and past laws, providing incidentally a wide ranging historical review of eugenics and the crimes that had been committed in its name in the United States and Germany. Together with Arno Motulsky's references to German eugenics in a splendid presidential address, these provided, most appropriately in Berlin, a sort of genetic catharsis.

The third presentation in the symposium was given by Helga Kuhse (Monash, Australia) who discussed many of the now familiar arguments about embryo research in a practical and even pragmatic way. Since the theme was that early human embryos do not have a 'right to life', this was followed, not unexpectedly, by a heated discussion including the reading of a prepared statement from the audience.

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This was much less specialised, dealing with a very wide range of ethical issues including euthanasia,
patients being denied the best treatment because of a lack of resources, confidentiality, and the rights of minors to make medical decisions. One session was specifically devoted to genetic screening and the identification of disease carriers. Each session began with a five or ten minute introduction by each of two or three eminent speakers, followed by a full half hour of general discussion. The speakers were drawn from Britain, the Netherlands, and Sweden and the audience of doctors, scientists, ethicists, and newspaper columnists was well informed and articulate. Only a few speakers from the floor were tempted to develop their own ethical theories at length.

The session on genetic screening was opened by Bernadette Modell (UK) and M F Niemeijer (Netherlands). β thalassaemia provides a powerful argument (skillfully presented by Modell) for population screening, since it can result in a massive fall in incidence providing the rules are followed, that there has been intensive education of the population at risk and the support of the community and religious leaders has been obtained. However, the rules are not always what they seem and Modell described the very different approaches in the two halves of Cyprus. In the Turkish part of the island, the government decided to make it mandatory that all couples should be screened for carrier status and a certificate is demanded before a marriage can go ahead. This approach was rejected in the Greek south where such laws would be regarded as contrary to democratic principles. However, the archbishops made it a moral law and decided that the priests should not marry couples unless they could present a certificate showing that they had been tested. On balance it appeared that the Turkish method had the advantage because the government provided the resources to carry out the programme.

Niemeijer looked at some of the other implications of progress in genetics. He showed the audience how DNA technology has widened the scope of screening and carrier detection for autosomal dominant and X linked disorders, as well as for some autosomal recessives. He stressed the currently unsolved ethical problems and psychological issues in presymptomatic diagnosis of diseases, where therapy is impossible at present. Variability of a dominant disorder may influence the choices of relatives either to take a test themselves or to use it for prenatal diagnosis. Like many other speakers at the Conference he stressed the need for confidentiality in handling data to prevent social damage, and identified the need for closer association between geneticists, counsellors, and patient organisations to help develop guidelines for future applications of the new genetics. Continuing public education on genetic principles was stressed as being important as well.

W J Appleyard (UK) and M A M de Wachter (Netherlands) opened a particularly interesting session on the doctor’s obligation to preserve the confidentiality of his individual patient, and how that might come into conflict with the doctor’s obligation to the community. Appleyard believed that the recent legislation in Britain (Data Protection Act 1984) was effectively removing control of confidential information on their patients from doctors. Appleyard, a paediatrician, was conscious of the extended health care team who might have access to patient records. The more people with such access the more difficult it becomes to guarantee confidentiality, and the doctor is particularly vulnerable since he retains his responsibility legally and as a member of an independent profession serving individual patients.

In the subsequent discussion Sir Douglas Black observed that confidentiality should be preserved except only for cases of overriding public health concern and for things that one would be prepared to justify in a court of law! De Wachter considered the ethical problems raised by AIDS and drew some analogies with those associated with inherited disorders. He asked whether one should tell patients when antibodies had been found and whether they should be reported to Health Authorities with grave implications for the doctor-patient contract of trust. How can doctors preserve their duty of confidentiality without hurting the public health? In connection with genetic disorders de Wachter referred to the President’s Commission.* This recommended that information on persons with genetic disease should only be released if four criteria could be satisfied. These were (1) all reasonable efforts had been made to obtain consent; (2) the condition was sufficiently severe to cause harm; (3) release of information would contribute to the avoidance of that harm; and (4) only information necessary to diagnosis and treatment would be released. (In Britain, the DHSS will shortly produce a ‘Code of Confidentiality in Personal Health Information’ which I hope will clarify the situation.) Clinical geneticists are particularly sensitive to the need for confidentiality, but in the past have probably quite rarely had to face the ethical dilemma on whether to tell or not, for example, when a parent refuses to allow the clinical geneticist to counsel their nubile children. The clinical geneticist does not wish to lose the con-

*The President’s Commission Study in Medical and Behavioural Science: Genetic Counselling, Superintendent Printing Office of US Congress, Washington DC, 1983.
Conference reports

dence of the family and he will attempt to persuade the parents rather than ignore their wishes. Release of information to insurance companies, etc, without the permission of the patient would of course be resisted.

However, John Fletcher is probably correct to stress that societal problems tend to sneak up on medicine and catch physicians unaware. He suggests also a certain complacency among medical geneticists that we can reconcile moral conflicts with the individual families and ignore questions that involve society’s interests. Perhaps we are leaning over backwards to avoid eugenics, but there are so many new and powerful scientific and diagnostic tools that medical geneticists must take a lead in reconciling the ‘old’ and the ‘new’ genetics, contributing fully to the debate on complex ethical problems, not excluding the crucial issue of the allocation of resources.

This meeting took the traditional view that a doctor must have the best interest of his immediate patient as a higher priority than the potential good of future patients and society as a whole. This led to the downward spiral of logic in which the future patient eventually becomes the present patient denied essential treatment, and also when times are hard clinicians may use the ‘decibel factor’ on behalf of their ‘acute’ patients to the detriment of prevention. However efficient and altruistic Health Service General Managers may be, they almost universally lack clinical training (according to several speakers, clinicians who become managers rapidly cease to be clinicians!). Priorities should be decided by experienced professionals but there needs to be clear, unified advice to politicians who otherwise will see fewer problems in a divided profession. Doctors were strongly advised to inform patients when they were denied optimum treatment because of lack of resources and no longer pretend that the decision had been made on clinical grounds.

There were many other interesting aspects of the Royal College of Physicians Conference, including the rights of minors to make their own decisions (if they are judged ‘competent’ why shouldn’t they?). Surprisingly little was said about the ethics of research on children too young to give consent. At present nothing can be done which is not for their benefit and the consent of their parents to research procedures is not relevant.

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