

# MEDICAL GENETICS

## Editorial

### Psychosocial genetics: an emerging scientific discipline

This issue of *Journal of Medical Genetics* contains eight papers covering a wide range of topics within the broad field of what can be termed 'psychosocial genetics'. This is not an invited collection, but a series of peer reviewed contributions that have been received unsolicited by the Journal and which all arrived within a few months of each other. Despite their diverse subjects, they have a number of features in common which led to grouping them in a single issue. They explore the attitudes of individual subjects and families to particular genetic disorders and to the tests being developed in relation to them; they also relate to the growing population emphasis of genetic services, notably screening programmes and genetic registers.

Two papers in this collection are concerned with cystic fibrosis; interestingly, each deals with the effects of programmes involving different approaches to carrier screening—school students and pregnant women and their partners; adults in a primary care practice setting form a third group studied in a paper to appear in a future issue. It is still too early to determine which, if any, of these approaches will prove suitable for overall service implementation, but it is of the greatest value that the psychosocial aspects of these programmes are being seriously addressed.

Late onset and variable dominantly inherited disorders form an important group of conditions where those at risk can increasingly be offered surveillance and genetic testing, with implications both for themselves and for their existing and future children. Genetic registers are an important element in any such programme, but the psychosocial aspects of registers and associated testing programmes have rarely been evaluated. The papers on familial ovarian cancer, neurofibromatosis, and Huntington's disease in this collection each explore aspects of prediction for these disorders which have general relevance, as well as importance for the specific disorder.

Some readers of *Journal of Medical Genetics* may question whether the field of psychosocial genetics is sufficiently rigorous and scientifically based to warrant publication and promi-

nence in the Journal by comparison with the longer established areas of cytogenetics, molecular genetics, and pedigree and population studies. I would argue strongly that it is—or at least that it can be, provided that authors are trained in the basic social sciences, or working closely with experts, and that the peer review process also involves such scientists. An increasing number of social scientists are working in or in close contact with medical genetics units, while academic departments in the social sciences are also recognising the value of the data and the issues that clinically based programmes offer. It seems likely that these rapidly developing links will enhance the validity of psychosocial genetics as a field of scientific activity in the same way as dysmorphology has been enriched by its interaction with clinical and molecular genetics.

Finally, will a comparable service related discipline emerge in the form of 'community genetics', 'public health genetics', or (as the paper by Shickle and Harvey suggests) 'clinical population genetics'? Such a development would, probably rightly, create great unease among many people, who will be reminded of how easily the 'public health' aspects of genetics could be (and have been) abused. Yet some framework is needed if disorganisation or inappropriate organisation is to be avoided. Perhaps the best safeguard against abuse will prove to be the existence of a body of well trained, critical, and involved social scientists and associated clinical geneticists, who will be able to ensure that any new development is exposed to detailed psychosocial evaluation. The speed of developments is becoming such that a body of workers like this is urgently needed; fortunately, the papers in this issue suggest that it is already evolving and should take an established place alongside other fields of human and medical genetics.

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