Letter to the Editor

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Ethical Aspects of Premarital Genetic Screening

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There is broad consensus among clinical geneticists as well as patient support groups that predictive testing of individuals at risk for genetic diseases raises serious ethical and legal problems. To address these issues, clear guidelines for predictive genetic counseling and testing have been established [1]. These rules of procedure are designed for individuals at risk for a particular disease who actively wish to obtain a genetic diagnosis rather than for population screening.

Recently, however, screening programs for healthy carriers of recessive diseases have been advocated. Tests were offered to pregnant women for cystic fibrosis [2] or even to premarital couples for hemoglobinopathies [3]. The predictive component and the psycho-social impact of such studies are best illustrated by the conclusion of Altay et al. [3] that '... this preliminary study attained its goal because two planned carrier marriages were cancelled...'.

There is no doubt that the prevention of inborn diseases such as cystic fibrosis or β -thalassaemia is a valuable goal of research and genetic counseling. On the other hand, we should be aware that the results of carrier screening, particularly if it is applied premaritally, can directly influence the tested individuals' decisions concerning their future life. Thus, it should be looked upon as a de facto predictive diagnosis for the probands who must be alerted in advance of the possible consequences of their participation; the usual kind of informed consent is not enough.

Moreover, the main psychological benefit of predictive testing of individuals at risk for a particular disease which they know from their own family is reduction of anxiety [4]. This argument for participation does not apply for persons from healthy families who are offered a carrier screening test for a disease which is more or less unknown to them.

As a consequence, the ethical implications of carrier screening programs appear to be widely underestimated and should be critically reconsidered. Premarital screening of healthy couples may be in the interest of health authorities and, depending on the socio-cultural background, also of family

heads who want to arrange a marriage between 'suitable' partners with little or no regard to individual motives such as love. We should keep in mind that even two carriers of a recessive disease have a realistic chance of becoming blessed with healthy children: do we really have the right to interfere unless they ask for it themselves?

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