

Ethical issues raised by mandatory genetic testing for female participants in the albertville games.

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In 1967, the International Olympic Committee (IOC) decided that participants in ladies' events would be required to undergo a biological "femininity" analysis : identification of the sex chromatin (Barr body) in cells sampled in the buccal mucosa. The sex chromatin in the nucleus of a cell shows an inactive X chromosome, and therefore in a woman, demonstrates the existence of two X chromosomes. The technique is painstaking and not very reliable.

The world over, many physicians and biologists had already objected to this practice.

For the 1992 Olympic Games, the IOC decided to take advantage of technical progress in molecular genetics. An analysis of amplified DNA is performed on cells from the buccal mucosa and a search carried out for genes situated on the Y chromosome which play a fundamental role in male sex determination.

The absence of genes carried by the Y chromosome, and in particular gene SRY, appears to be a criterion of femininity.

Clinical experience in using these genetic tests have shown how difficult they are to interpret in the case of sex-determination anomalies. This is well illustrated in the case of XY women who have a Y chromosome which carries mutations of gene SRY. Such women are normally feminine, they may even have children with the help of medically assisted reproduction. Doctors prefer to keep them in ignorance of this anomaly, since to reveal that they carry certain male genetic characteristics could bring about distressing psychological reactions. There have been such precedents in the context of the Olympic Games.

There are also XX men who evidence no sign of Y genetic material, and XYY men with two sets of Y chromosome genes.

Many physicians and biologists have recently protested against the use of these genetic tests. Those with the longest practical experience of such biological analytic techniques are aware of the complexity of the problem and reject the idea that sex definition should depend entirely on a genetic test.

Ethically, recourse to genetic testing raises many objections which are apparent in the Opinions of the National Consultative Ethics Committee for Health and Life Sciences (CCNE), in particular the Opinion on genetic tests of 24th June, 1991.

Sampling cells and analysing DNA for genetic test research should be limited to clinical applications and as things stand, should be connected solely to medical or judicial indications. This is not so in the case considered. We are only dealing here with sports' events. The only likely consequence, far from being medical, would be to prevent participation in a competition.

"For any determination of the characteristics of an individual's genome...the subject's consent is to be given for specific analysis". There is no such thing as consent in this case since the genetic test is mandatory. A person who did not take the test, would be barred from the competition. Such discrimination would be unacceptable in view of the principle quoted above. This comment is reinforced by the fact that some of the competitors are minors. One might well consider whether parents or guardians should not be asked for their consent.

The CCNE in the Opinion quoted above also wrote : "no result concerning the characteristics of the genome of an individual is to be provided to parents, third parties, or to any public or

private organisation without the explicit consent of the individual" This is motivated by the demands of confidentiality. But in the case under review, it is clear at the outset that if there are signs of male sex-determination the secret is revealed by the fact that the competitor is eliminated.

The National Consultative Ethics Committee recommended in another Opinion on the subject of identity testing by DNA analysis (15th December 1989) that robust protection be given as regards the special case of proof, i.e. decision by judicial authority, and use of an accredited laboratory.

No such equivalent protection is provided in the field of sports.

Apart from noting this disregard of previously quoted Opinions of the National Consultative Ethics Committee, two more legal and psychological points need to be made.

In legal terms, one question cannot be ignored : what would be the legal identity status of a female athlete after a test has shown that genetically, she is not a woman ?

Furthermore, she could well suffer severe psychic trauma.

Finally, if such genetic testing were to be allowed, it would surely become common practice with the effect of discriminating between individuals to the detriment of their liberty.