

RECOMMENDATION NUM. 1.512 (2001).* PROTECTION OF THE HUMAN GENOME BY THE COUNCIL OF EUROPE

1. The Council of Europe's Parliamentary Assembly notes that the human genome international research project, in view of the numerous and unimaginable consequences that it might have for medicine and for the animal and plant world, conjures up scenarios for all humanity that raise numerous ethical questions, while holding out the promise of enormous improvements in the quality of life.

2. The protection of human dignity should be the guiding principle for the handling of the Human Genome Project.

3. The genetic age will dawn with the completion of the project: diagnosis will become objective, and it will be possible to identify the presence of genetic disorders or a genetic predisposition to illnesses at an early stage. In many cases, gene therapy will become possible, and this will basically give rise to a form of genetic engineering designed, for instance, to avoid the development of a tumour in an individual found to be at risk. It might also be applied to other illnesses, such as hypertension, diabetes, Alzheimer's disease, osteoporosis, certain psychiatric disorders, etcetera.

4. At the same time, the Assembly is aware of the enormous ethical impli-

cations of further research on the human genome, including some of a negative nature. These include questions regarding the cloning of cells, the conditions ruling genetic testing and the divulging and use of obtained information.

5. In this connection, the Assembly is fully aware of the now well-known fact that laboratories, with their associated databanks, are already actively at work on DNA separation in certain European countries and enjoy the financial support of prominent pharmaceutical companies.

6. The Assembly is also aware that substantial economic interests are at stake in the Human Genome Project, by virtue of the very fact that it might hold out incalculable opportunities for preventing illness and improving treatment, as it involves many public and private research centres to which considerable financial resources will be allocated.

7. The Assembly is of the opinion that the results of this grandiose research effort—in which the United States has the lead over Europe—must be made available to all, genetic information being a common human heritage, as set out in article 1 of the Universal Declaration on the Human

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Genome and Human Rights, adopted at Unesco in Paris on 11 november 1997. The Assembly in particular refers in this context to the Council of Europe Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine—Convention on Human Rights and Biomedicine (ETS num. 164) as well as its own Recommendations 1425 (1999) on biotechnology and intellectual property and 1468 (2000) on biotechnologies.

8. In particular, the Assembly is aware that the prospects opened up by the discoveries associated with the Human Genome Project pose a whole series of ethical problems, essentially concerning such fundamental issues as the use of genetic information for preventive purposes and possibly a presumed right, at a later stage, to take preventive action when certain genetic information is obtained. However, a crucial question will be the assessment of who will have which rights to use the information: the case of insurance companies, employers, parents, schools, etcetera.

9. The Assembly calls, *inter alia*, through the establishment of a Euroforum on Human Genetics, for the widest possible participation by citizens in the discussion on the human genome through the involvement of the European media and suitable and accurate information by the Council of Europe.

10. The Assembly expresses the wish that the scope of action of the above-mentioned authority should not be confined to Europe, but that it may become part of a world authority under the aegis of the United Nations. To this end, the Assembly advocates that the

necessary contacts be established with the appropriate bodies within the UN and UNESCO as soon as possible.

11. In view of the above, the Assembly recommends that the Committee of Ministers:

i. Invite every Council of Europe member state concerned to set up, under its own domestic legislation, a national authority having the express task of monitoring, informing and advising on the compliance of research on the human genome with universally recognised ethical and moral principles of respect for life and human dignity.

ii. Set up, at European level as well, and more specifically in the context of the Council of Europe, a body or authority to fulfil on a permanent basis the task of monitoring the development of the Human Genome Project research process, ensuring respect for ethical principles in the context of research on the human genome, assessing the effects of such research also regarding health risks, and giving thorough consideration to all the ethical aspects of the project, and consider in this context the role of the Steering Committee on Bioethics (CDBI).

iii. Ensure that these bodies for monitoring research on the human genome will familiarise the European public with new possibilities for progress in genetics in terms of information and technology and serve also to promote campaigns to inform and educate the public, in particular the health profession.

iv. Make sure that consultation of the European authority be mandatory, and that it formulate an opinion when conventions are drafted on this subject in the context of the Council of

Europe and codes of ethics produced; such a body should also have free access to important information on genetics and be able to carry out its own inspections of public and private European research institutes.

v. Ask member states to sign, ratify and implement the Convention on Human Rights and Biomedicine.

vi. Ask all Council of Europe member states to strive to change the basis of patent law in international fora, as far as the ownership of human being tissue and genes is concerned, into law pertaining to the common heritage of mankind.