Letter to Members of the European Parliament from
the European Society of Human Genetics

Re: Fiori report on the ethical, legal, economic and social implications of human genetics

Ammendment Deadline November 22; Voting on 29 November 2001

Dear Sir/Madam

You are going to be asked to vote on the Report presented by Mr Francesco Fiori on the ethical, legal, economic and social implications of human genetics. **It is an important vote because, as the report now stands, it risks closing the door on promising research into treatments for serious diseases such as Parkinson's disease.** What follows are the considered views of the European Society of Human Genetics (ESHG), who are mindful of protecting the future interests of the patients and families that ESHG members seek to help.

The ESHG members are AGAINST the proposals for

o A complete ban on all forms of cloning, including therapeutic cloning. Indeed, the report specifically denies distinction between therapeutic cloning (which we support) and reproductive cloning(which we agree should be banned).

o A prohibition of funding for stem cell research on supernumerary embryos and that all these embryos must be kept available to assist couples with infertility problems.

o A prohibition of prenatal screening aimed at pre-implantation embryos with the best chances for survival.

o The report's proposal in its last article to have these guidelines take priority over national procedures, i.e. to relinquish the subsidiarity-principle of the EU."

This document has been carefully examined by the board members of the ESHG. They consider this report an important one, that contains many suggestions to improve the management of genetics in Medicine and the delivery of genetic services. Despite that, they urge you not to accept this document as it contains several paragraphs, mainly dealing with the use of embryonic stem cells for research which are unsound scientifically, very debatable or both. You will find a list of them with our comments in bold, in the attached document.

Recent developments in research have indicated that human embryonic stem cells have enormous potential for adding to our knowledge of and relieving suffering from many serious

human diseases for which there is currently no cure or effective treatment. Yet the use of human embryos in research is highly controversial and raises complex ethical questions. Scientists acknowledge the reality of public concerns.

Adult stem cells are cited as an alternative to embryonic stem cells. Clearly the use of adult stem cells is an option which ought to be developed fully, but they create problems of their own which would make it premature to drop work on embryonic stem cells at this stage. Amongst these problems is their accessibility. They are hard to find and few in number (less than 1 in 100 million). Maintaining their growth and differentiation capacity is difficult and may raise questions of safety that will need to be addressed.

Compared with adult stem cells, we know now that embryonic stem cells are accessible (with a 50% efficiency of isolation). They are pluripotent, which means that they can differentiate into all types of cell found in the body. Animal experiments show they can form functional tissues after transplant and clinical trials show they have not found tumours and are still working more than 2 years after transplanted.

Given the potential of adult stem cells, is it ethical to continue using embryonic ones? Logically it seems inappropriate to stop one productive line of research just because another seems promising. There are also ethical problems in doing such a disservice to potential beneficiaries from the outcomes of embryonic stem cell research. Research using embryonic stem cells needs to proceed in parallel with that on adult stem cells. The lines are complementary and it is not clear that adult stem cells will replace or make redundant the use of embryonically derived stem cells.

It is appropriate that public confidence and support is maintained and an appropriate regulatory framework is developed. Embryonic research requires a compromise between respect due to a potential life to be contrasted to the respect owed to someone who is alive and stands to lose their life by virtue of our decision not to act – not to permit research to proceed.

There is a need to manage the regulatory process to ensure the continuing compatibility of scientific potential and societal norms, exercising wisdom in the placing of boundaries at the appropriate point on those “slippery slopes” that may exist. In forming regulations to control

embryonic stem cell research and development it seems sensible to lay down a few broad principles rather than seeking to micro-manage the future biological possibilities.

Realistically it seems unlikely that a satisfactory European consensus on the acceptability of using embryonic stem cells in biomedical research will emerge. A pragmatic solution to the political problem of divergent cultural and ethical values appears the best way forward. This pragmatic approach is to recognize national approaches and respect them. There is a need to develop generosity with each others position and avoid too quick a rush either to condemnation or to the imposition of uniformity where, in reality none exists and it is impossible to manufacture.

Given the importance of this research and the potential it holds out, the European Institutions should recommend to the member states that consideration be given to putting in place an appropriate national regulatory framework. However care should be taken to avoid premature or too heavy-handed restrictions that will close down opportunities prematurely.

Finally, the principle of subsidiarity should not be lightly abandoned. The impossibility of harmonization is obvious, but this European diversity should be embraced. If member states have gone through their own due process then the validity of the conclusions reached should be respected and endorsed as right for them. This will bring mutual benefits and is part of the added value that comes from being part of the European Community. This, ultimately will be the soundest route for determining whether the promise that this research is holding out is real and whether it can be realized for the benefit of all who need and wish it in the European Community.

We hope that you understand how important it is not to close the door to promising research until it has been evaluated. The European Society for Human Genetics strongly pleads with the Members of the European Parliament to accept these arguments in the interests of the patients and their families.
We thank you in advance for your understanding.

Yours sincerely

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