



To: UK MEPs

21 April 2009

By email

Dear Colleague

**Proposal for a Council recommendation on a  
European action in the field of rare diseases**

I am aware that the European Parliament is due to debate, this Thursday, a report on the proposal for a Council recommendation on a European action in the field of rare diseases (COM(2008)0726 – C6-0455/2008 – 2008/0218(CNS)) from the Committee on the Environment, Public Health and Food Safety (Rapporteur: Antonios Trakatellis).

I write to draw to your attention to advice of the UK's Human Genetics Commission (HGC) that we consider to be relevant to this recommendation, specifically the proposed amendment 15 (to Paragraph 1 – point 5 a (new)), which recommends that Member States:

***“(5a) encourage efforts to avoid rare diseases which are hereditary, and which will lead finally to the eradication of those rare diseases, through:***

***“(a) genetic counselling of carrier parents; and***

***“(b) where appropriate and not contrary to existing national laws and always on a voluntary basis, through pre-implantation selection of healthy embryos.”***

We note that if this recommendation were construed as promoting directiveness in genetic counselling it would represent a significant departure from established practice and accepted clinical ethics.

The Human Genetics Commission is the UK's advisory body on developments in human genetics and their implications for individuals and



society. In our 2006 report, *Making Babies, reproductive decisions and genetic technologies*, we emphasised the importance of non-directiveness in genetic counselling, respect for the reproductive autonomy of individuals and for the welfare of children who may be born, and respect for the dignity of people affected by genetic conditions. We would draw your attention to our conclusions in *Making Babies* and elsewhere, which include, among other things, that:

- the reproductive autonomy of all people should be respected where its exercise does not unreasonably impact on the autonomy of others, or threaten others with significant harm; individuals' reproductive choices should be defended from any pressure or inducement, whether from health professionals, social attitudes or government policies
- all pregnant women should have equal access to appropriate, good quality, properly evaluated screening programmes; participation in these programmes should be voluntary and no assumption should be made that people will automatically take up the offer of prenatal screening
- a strong programme of research aimed at better treatments for genetic conditions, coupled with availability of appropriate services for those with genetic conditions is the best response to some of the ethical objections to prenatal screening
- non-biased information from a wide range of sources should be available for those who have known, heritable genetic conditions in their families, including information about genetic disease, available screening programmes, reproductive options, and support for those living with genetic disease
- genetic counselling should be available to those with heritable genetic diseases in their families; this counselling should be non-directive and guided by the patient's wishes and needs; accordingly, genetic counselling should not be used as an opportunity to encourage people to choose a particular reproductive option: to do so would threaten the professional integrity of counsellors and undermine the non-directive ethos of genetic counselling
- the reproductive option chosen by prospective parents should be the result of a free choice among the range of options available (including the possibility of having an affected child); in particular, prospective



parents should not be actively encouraged to opt for preimplantation genetic diagnosis (or any other option) just because it is available: PGD is a demanding, expensive and technically complex service, and offers only a limited likelihood of a resulting live birth

- the aim of 'eradicating rare hereditary diseases' from a population may imply lack of respect for the dignity of people living with genetic conditions and, in particular, express the morally unacceptable proposition that it is undesirable to have people with such conditions as members of society.

Copies of *Making Babies* can be downloaded from the HGC's website:  
<http://www.hgc.gov.uk/Client/document.asp?DocId=112&CAtegorId=10>

Yours sincerely,

Professor Jonathan Montgomery  
Chair, Human Genetics Commission