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**European Society
of Human Genetics**

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TO THE MEMBERS OF THE EUROPEAN PARLIAMENT
CONCERNING PLENARY VOTE THURSDAY APRIL 23, 2009; 12.00 - 13.00 h.

date: April 20, 2009
our reference: 09.030
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subject: Urgent reaction European action rare diseases
(COM(2008)0726 - C6-0455/2008 - 2008/0218(CNS); A6-0231/2009)

Dear Member of the European Parliament,

As representatives of professionals working in the field of human genetics we contact you because of an urgent matter concerning the text of the document:

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))
Committee on the Environment, Public Health and Food Safety
Rapporteur: Antonios Trakatellis

Though we fully agree with large parts of the text, some sections have stirred alarm among professionals working in the field of human genetics. Though probably stated with the best of intentions, the wording of these sections is reminiscent of eugenic practices from the previous century. We hereby express our deep concern and we urge the Parliament to object to these particular text sections, and to reject the proposed Amendment.

The problematic sections concern:
Amendment 15:

*"Recommendations to Member States - on page 12 of the document
Paragraph 1 - point 5 a (new) Proposal for a recommendation*

Amendment

(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."



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Our objections concern the way in which the aim of genetic counselling is related to eradication of hereditary disorders. Since many years it is clear that genetics in health care should aim to help people understand and cope with genetic disorders in their family. This has been stated in several EU official documents (please find more information at the last section of this message).

Non-directiveness in counselling and "informed decision making" are central goals in genetic health care. Exceptions to non-directiveness are nowadays only found where there is health gain for the person involved, such as in neonatal screening programs, but never in reproductive choices. Prevention in public health might be acceptable when we speak about the avoidance of external influences (rubella infection, teratogenic effects due to medication, radiation as a cause of mutations). But "eradicating" rare diseases by stimulating certain reproductive choices as a public health strategy is not acceptable from the professional standard of human geneticists in Europe.

Though reducing the live-birth prevalence of children with a hereditary disorder may be the effect of genetic counselling, it is not its aim.

The importance of non-directiveness in reproductive issues is a central characteristic of human genetics after the atrocities committed in the name of eugenics in the first half of the twentieth century. It implies that a patient or a couple should be able to make an informed choice consistent with their own values on the basis of adequate information. Any pressure from the health professional, from public health policies or governmental institutions, or society at large, should be avoided.

**We urge members of Parliament to vote against Amendment 15 on
THURSDAY APRIL 23, 2009; 12.00 – 13.00 h.**

We invite the members of Parliament to respond and let us know whether they share our concern.

Further documentation on the standard view on genetic counselling can be found in:

Opinion 6 of the European Group on Ethics of Science and New Technologies (EGE, 1996) on Prenatal Diagnosis
http://ec.europa.eu/european_group_ethics/docs/opinion6_en.pdf

No prenatal genetic testing must be imposed by law, by public health services or by any other institution or person (2.2). The principle of free and informed consent implies that the genetic counselling to the woman or the couple must be non-directive, professional and respectful of their autonomy. The decision to terminate the pregnancy or to give birth to a child with a disease or a disability is a very difficult one. The interest of the individuals concerned should take precedence over any collective benefit to society. The final choice of whether to continue or to terminate the pregnancy is the prerogative of the woman or the couple alone. No discrimination should be made as a consequence of either of these decisions. Moreover, the woman or couple should not be later penalised for the choice they have made. Good medical and social conditions must be ensured, when the pregnancy is continued, for people with disabilities, members of the family or people caring for the disabled person, avoiding any exclusion or discrimination against them (2.6).

Report and 25 recommendations of the EU expert Group on Ethical, legal and social aspects of genetic testing (2004). This group was chaired by a member of the EU parliament and comprised patients representatives and industrials
http://ec.europa.eu/research/conferences/2004/genetic/recommendations_en.htm

In the text accompanying the Recommendation 9 on Genetic counselling, it is written (P. 14 of the Recommendations and P. 57 of the report): "Non-directive counselling must be the rule. The main goal of genetic counselling is to help individuals or families understand or cope with genetic disease, not to decrease the incidence of genetic disease."

On behalf of the Public and Professional Policy Committee of the European Society of Human Genetics,

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