

## **Subject: EU Temporary Committee on Genetics Recap overview by the European Society of Human Genetics**

\* In the beginning of this year the European Parliament established the 'Temporary Committee on human genetics and other new technologies in modern medicine'. This committee was chaired by Mr Goebbels of Luxemburg, and Mr Fiori of Italy was the rapporteur.

\* During the year, this committee has been hearing evidence from many parties, including several geneticists from the ESHG and HUGO, patient groups, industry, environmentalists etc.

\* The committee has been gradually building first a background document and subsequently a draft report.

\* The background document is excellent in width, depth, and comprehensibility for a wide public, better and certainly more up-to-date than most textbooks or popular treatises.

\* The draft report was by and large a balanced and insightful document, which might have become a very sound basis for balanced European policy in these emerging fields.

\* Before the final adoption session on November 5, nearly 600 amendments were submitted, from moderate to very conservative, including many amendments which are scientifically unsound and contradictory to the background document's information.

\* A coalition of Christian rightwing, Christian Democrats and Greens voted en bloc for the most restrictive amendments and against all moderate amendments.

\* This appears to have reversed many of the considered conclusions of a potentially very valuable EU-document, into which many months of experts' and committee time had gone. It is as if in most articles the word NOT had been added.

\* Striking points from the final report are:

- o A complete ban on all forms of cloning, including therapeutic cloning. Indeed, the report specifically denies distinction between reproductive and therapeutic cloning.

- o A prohibition of funding for stem cell research on supernumerary embryos. 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 In addition, the report proposes in its last article to have these guidelines take priority over national procedures, i.e. to relinquish the subsidiarity-principle of the EU.

\* There was an attempt to rush the report through a plenary European Parliament hearing and vote, by proposing to bring it forward to November 14, from the end of November. This would have implied that it would precede - and greatly influence - the discussion and vote about the 6th Framework report (the so-called report-Chaudron), which was on the agenda for this date.

\* This has not been possible because the EU's translation has not been able to provide MPs with a translated version of the report on time. The Parliament thus objected on 12 or 13 November by a modest majority (169 of 290), against putting this on the agenda for the 14th and postponed it to late November, with an amendment deadline of 22 November.

\* The 6th FRP (Report Chaudron) has been duly debated and voted upon, with the following results:

- o A general prohibition of all stem cell and embryo research has not been accepted (but with a close result, typically 150-200 votes in favour of all amendments of the MP Scallon).

- o Article 3 ('Ethics clause') excludes from Community funding:

- + human germ line engineering (Art. 3.2, 3rd indent),

- + the creation of embryos for research purposes (Art. 3. 2, 2nd indent),

- + reproductive cloning (Art. 3.2, 1st indent) as well as

- + therapeutic cloning, i.e. somatic cell nuclear transfer  
(Art. 3.2, 2nd indent).

While the first three have a wide consensus and will meet with little - if any - dissent of the scientific, patient, medical or industrial community, the latter will be much deplored by researchers and clinicians who are looking for therapy for mitochondrial diseases, which include several severe, late-onset neurological disorders, forms of blindness and deafness, for which no prenatal diagnosis and preventive options are available because of the mitochondrial form of inheritance.

- o Not excluded from Community funding are:

- + research on 'surplus' embryos (not older than 14 days) which are 'destined for destruction' if such research is allowable in the Member State concerned

- + research on existing (embryonic) stem cell lines, which reflects to some extent the position President Bush took earlier this year.

- + Research activities on newly created embryonic stem cells are not explicitly mentioned, i.e. they are in principle fundable under the programme, although research on other stem cells, such as adult stem cells, shall have priority. It is left open whether research activities involving newly created embryonic stem cells may be funded, where the stem cells were derived from embryos created solely for research purposes.

The Board of the ESHG believes that all efforts must be made to inform Members of the European Parliament of concerns about some of the scientific statements in the (amended) report-Fiori and ask them to consider voting against these or voting for their significant amendments. The ESHG has proposed amendments which are also on this website..

The European Parliament reports and documents can be found on the website of the EU:  
<http://www.europarl.eu.int/meetdocs/committees/gene/>.