

# Human Fertilisation and Embryology Bill

Briefing for House of Lords 3<sup>rd</sup> Reading, 4 February 2008

**Prepared by the Academy of Medical Sciences, Medical Research Council, Royal Society and Wellcome Trust and supported by the Association of Medical Research Charities.**

We continue to support the aims of the Human Fertilisation and Embryology (HFE) Bill to modernise and update the Human Fertilisation and Embryology Act (the Act), ensuring it keeps pace with scientific and medical developments in the field whilst maintaining public confidence in the regulatory framework around such research.

We are confident that the original bill and the consequent debates and amendments in the House of Lords have created legislation that, when enacted, will maintain an environment in the UK where scientists are able to work at the cutting edge of stem cell and embryo research within clear and tightly-regulated guidelines.

The UK's strengths in this field present valuable opportunities to influence the international agenda, drive the translation of basic research towards clinical benefits and attract skilled scientists and international investment in stem cell research. This research has the potential to provide avenues for treatments of disorders ranging from developmental abnormalities in young children, stroke, cancer, HIV Aids, diabetes and Parkinson's disease.

The Bill will enable important scientific and medical research to be undertaken. In particular it will give scientists the ability to create Human Admixed Embryos (or Inter-Species Embryos) under licence, which we believe will be a powerful research tool in addressing some of the conditions described above.

In the rest of this brief we outline some sections of the Bill where we have previously expressed concern, and describe our current position and understanding.

1. Definitions of Human Admixed Embryos
2. Exception to requirement for specific consent for use of pre-existing cell lines
3. Special exceptions to consent provisions in relation to children and storage and use for research
4. Development and application of therapies using stem cells

## **1 Definitions of Human Admixed Embryos**

We strongly support provisions to allow the creation of human admixed embryos (previously referred to in the Bill as 'Inter-Species Embryos') for the purposes of research under licence.

The ability to create these entities within a robust regulatory environment will enable potentially life saving therapies to be developed for a number of debilitating human conditions ranging from childhood diseases, diabetes, cancer, HIV AIDS, Parkinson's disease and spinal cord injuries and many others.

We appreciate the efforts that peers have made in ensuring that the definitions of Human Admixed Embryos are scientifically and legally robust, building for example on the work of the Academy of Medical Sciences and others.

## **2 Exception to requirement for specific consent for use of pre-existing cell lines**

The consent provisions contained in Schedule 3 of the bill extend the requirement to obtain specific consent to create an embryo to the use of any human cells. This would include artificially created stem cell lines which may have been made from human tissue originally collected with consent from an individual, to create an embryo, both a first generation embryo and any subsequent embryos created from the first.

We are concerned that this requirement effectively blocks the use of many current stores of cell lines in research to investigate origins of disease, including cell lines from patients with specific rare conditions.

One example of this is a collection of cells taken from patients with a rare form of early-onset Alzheimer's Disease, for which there are only five families in the world who possess this particular combination of genes and proteins. Embryo research on these samples would allow researchers to create samples of brain tissue enabling further study.

We understand that the Government has accepted the compelling case put forward by scientists, and has made a commitment to resolve this issue.

We would welcome the introduction of a limited exception to permit use of existing lines where it is not reasonably possible (rather than simply inconvenient) to obtain consent; where there is no alternative source of tissue and where the individual or relative is unidentifiable; and the research is deemed to be important. This will ensure that, in exceptional and deserving cases, vital resources are not wasted and important research can be carried out.

### **3 Special exceptions to consent provisions in relation to children and storage and use for research**

At Report Stage we repeated our concerns that the effective consent provisions introduced do not make provision for consent to be given by parents on behalf of their children to use their somatic cells for the creation of an embryo or human admixed embryo for research purposes. The effect of this would be that research into childhood diseases, including lethal genetic disorders, using somatic cell nuclear transfer (SCNT) could not go ahead.

We understand that after hearing some very strong and persuasive scientific arguments, the Government is reconsidering the current consent requirements regarding consent for children. We would welcome a commitment to develop suitable provisions to allow for parental consent in appropriate situations.

### **4 Development and application of therapies using stem cells**

At the Report Stage a number of amendments were tabled which would enable the HFEA to license the creation of embryos for therapeutic purposes. All of the organisations represented in this briefing strongly support the development of an environment where the results of medical research are translated into health benefits as quickly and efficiently as possible. We would welcome clarification from the Government that previous or future legislation will not act as a legal barrier or cause delays in scientific research involving the creation of embryonic stem cell lines for therapeutic application.

#### ***Organisation Contacts***

<i>Academy of Medical Sciences:</i>	<i>Helen Munn 020 7969 5234</i>
<i>Association of Medical Research Charities:</i>	<i>Simon Denegri 020 7269 8820</i>
<i>Medical Research Council:</i>	<i>Catherine Elliot 020 7670 5481</i>
	<i>Simon Wilde 020 7670 5190</i>
<i>Royal Society:</i>	<i>Anne Simpson 020 7451 2530</i>
<i>Wellcome Trust:</i>	<i>Nancy Lee 020 7611 8751</i>