HUGO ETHICS COMMITTEE STATEMENT ON STEM CELLS November 2004

The HUGO Ethics Committee addressed issues directly related to stem cell technologies in its *Statement on Cloning (1999)*, and here reiterate the following conclusions drawn therefrom:

- Therapeutic cloning is acknowledged to be of value;
- Deliberate creation of embryos for research is widely regarded as unacceptable;
- However, creation of 'embryos' by somatic cell nuclear transfer to grow stem cells is suggested to be permissible where deemed to be both of indisputable benefit and the only course of action available;
- Reproductive cloning of an existing human being is firmly advised against.

The Committee is of the opinion that progress in stem cell technologies creates further ethical issues that warrant particular attention and elaboration. Stem cell science has the potential to revolutionise medical care. Its impact is therefore of great importance not only to the scientific community, but also to the world at large. Given the recent explosion of knowledge about, and public interest in, stem cells, the Committee deems the issues to be particularly pressing, particularly in relation to embryonic stem cell research. In considering them, the Committee recognises the variation in national laws. The Committee subscribes to the four principles outlined in its *Statement on the Principled Conduct of Genetic Research*:

- Recognition that the human genome is part of the common heritage of humanity;
- Adherence to international norms of human rights;
- Respect for the values, traditions, culture and integrity of participants in research;
- Acceptance and upholding of human dignity and freedom.

Stem cells are undifferentiated, self-replicating cells that can be stimulated to develop into more specialised cell types. Stem cells of various types have been used in medical therapy for a number of years, most notably in bone marrow transplants. It is hoped that the regenerative capacities of stem cells at earlier stages of differentiation can be harnessed in order to develop therapies for disorders and illness caused by organ or tissue dysfunction. The implications of the use of stem cells in research, and perhaps later in general therapeutic practice, are controversial due to questions of their source, their actual application, the further potential applications of related technologies developed in the process of research, and the effect these may have on society as whole.

The HUGO Committee recommends that:

1. Investigation of all potential sources of stem cells should be pursued

1.1 Embryonic stem cells

Embryonic stem cells can in principle be derived from; embryos deliberately created by fertilisation; aborted embryos; 'spare' embryos (being those supernumerary to the intended purpose, and which would otherwise be destroyed, for instance in the context of IVF); somatic cell nuclear transfer (cloning techniques); parthenogenesis.

- Differing personal, cultural, spiritual and religious beliefs regarding the status of embryos should be respected.
- Research should not be confined solely to the use of 'spare' embryos. These embryos may well provide misleading data or deficient stem cell lines due to their possible lack of reproductive viability, and may be further damaged by the freezing/thawing process undergone.
- Discussion should continue as to whether all constructs created by somatic cell nuclear transfer, parthenogenesis or other methods apart from fertilisation should be understood as 'embryos' in the conventional sense.

1.2 Cloning techniques

- In the light of the potential utility of therapeutic cloning in avoiding immunological rejection of tissues and organs derived from stem cells and the knowledge of the reprogramming and proliferation of cells that it facilitates, research into therapeutic cloning should be encouraged.

1.3 Deriving gametes directly from stem cells

- It is emerging that stem cells derived from embryos produced by nuclear transfer can be stimulated to differentiate directly into gametes. It should be recognised that the direct differentiation of embryonic stem cells into gametes has the potential to undermine the strict boundary between therapeutic and reproductive cloning. Theoretically, individuals could therefore reproduce through fusion of their own gametes. Such (a)sexual reproduction provokes its own distinctive concerns for parent, child and society as it completely diverges from the established pattern of a child being the product of a union of two people. As such it should not be permitted.

2. The interests of stem cell donors and recipients of therapy should be respected

- Donors of biological material for deriving stem cells should be protected from coercion, especially given that potential donors will most likely be undergoing treatment and thus may be emotionally vulnerable or physically weak. The appropriateness of requesting a donation must be carefully assessed.
- Donors of ova for the purpose of therapeutic cloning should likewise be protected from coercion. Whether ova are obtained from live women directly, ovaries removed for other medical reasons, or aborted foetuses, informed consent should be obtained.
- The possibility that stem cell lines could transmit disorders or unpredictable epigenetic abnormalities to the recipient should be recognised and guarded against.
- Where appropriate, recipients of therapy and user groups should be forewarned of possible complications resulting from difficulties with the quality of stem cell lines or the immunological rejection of therapies.
- Stem cell therapies may be developed that alleviate devastating and degenerative disorders. There should be equity of access to this humanitarian benefit.

3. The repercussions that stem cell therapies may have for society as a whole should be carefully considered

- Stem cell therapies should be administered responsibly in the face of fears that they have the capacity to create or compound negative manifestations of certain conditions. Prevention or treatment of disease may cause increased stigma and antipathy towards those already living with the condition, whilst also leading to the risk of a new and insidious eugenics, affecting both those living and those yet to be born.
- Individual differences and free choice should be protected, and the integrity and rights of individuals should be upheld accordingly.
- Attitudes towards the creation, destruction and commodification of life must be assessed, challenged and justified in the face of stem cell technologies. The dangers of instrumentalisation or trivialisation of life warn of the potential consequences for our understanding of the self and the perception of the individual.

4. Freedom of research should be fostered

- The independence of scientists, which underpins the advance of knowledge and understanding, should be supported and sustained.
- Individual creativity and innovation should be encouraged, and where necessary and relevant, the intellectual property of researchers protected accordingly.
- Tensions must be recognised and resolved between these private rights of scientists and the legitimacy of the general claim that genomic knowledge should foster maximum benefit to humanity as a whole.

5. Coherent regulation should replace prohibition of research

- Blanket prohibition of certain areas of research is antithetical to scientific progress. Where necessary, appropriate regulatory processes should be implemented in its place.
- It is desirable that countries present a coherent attitude towards research, rather than shirking moral responsibility by outlawing the use of embryos in their own country but allowing their import; by allowing use of embryos produced only before an arbitrary timeline; or by outlawing government funded research but granting private bodies free reign. Congruence should also be sought with existing relevant legislation (e.g. on abortion).

6. Given the rapid pace of change and development in stem cell research, the issues addressed in this statement should be kept under review.

HUGO Ethics Committee

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- Dr Kare Berg (Norway)
- Dr Jose Maria Cantu (Mexico)

- Dr Abdallah Daar (Oman)
- Dr Ishwar C Verma (India),
- Dr Kazuto Kato (Japan)
- The Honorable Justice Michael Kirby (Australia)
- Prof Bartha Maria Knoppers (Canada), *Retired Chair*
- Prof Darryl R.J. Macer (Japan)
- Dr Thomas H. Murray (USA)
- Prof Ren Zong Qiu (China)

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