Ms. Marie Kawaja Inquiry Secretary House of Representatives Standing Committee on Legal and Constitutional Affairs Parliament House CANBERRA ACT 2600

Dear Ms. Kawaja,

Re: SUBMISSION TO THE HOUSE INQUIRY AND TO SCIENTIFIC ETHICAL AND REGULATORY ASPECTS OF HUMAN CLONING.

The Human Genetics Society of Australasia commends the Australian Health Ethics Committee of the National Health and Medical Research Council for its policy statement on Scientific, Ethical and Regulatory Considerations Relevant to Cloning of Human Beings. The Human Genetics Society of Australasia has previously produced a policy on Human Cloning, which I attach as an appendix to this letter.

The document presents a thorough examination of this area. It is necessarily rather long and technical. This may be largely unavoidable; however, if there was some opportunity to shorten and simplify the document it may be beneficial.

The Human Genetics Society of Australasia strongly supports the UNESCO declaration which states that the practice of reproductive cloning of human beings should not be permitted. We also support the introduction of uniform legislation in all states and territories to cover this area.

The Human Genetics Society cannot see any circumstance either medical or social, which would make the cloning of an individual desirable.

Publicity that is aimed to clarify for the public the distinction between the cloning of human beings and the cloning of DNA would be of value.

The Human Genetics Society does not support the concept of setting up a nonhuman primate research facility as this would involve an enormous expense, and we believe that the research can equally well be done on human tissue.

We believe that research to allow the use of de-differentiated somatic cells, or embryonic stem cells for transplantation is of substantial medical importance. Research in this area should be permitted and supported. The HGSA does not see embryonic stem cells grown as cells in culture in any way equivalent to human embryos, and believes that research should be allowed to proceed with this form of research in Australia.

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We would suggest that consideration be given to a national regulatory committee for reproductive and genetic technology with appropriate legislation making it essential that any group undertaking research in Australia would first submit its proposal for research with human material in this field to such a committee. This committee could then determine the extent of research which could be undertaken on human embryos. The HGSA hopes that eventually a national agreement might be reached in this area, which could hopefully be achieved through the International Federation of Human Genetics Society, or possibly through WHO and UNESCO. This might produce a common code of practice.

If there are further questions you would like the HGSA to address they could be done by contacting:

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Yours sincerely,

DR. AGNES BANKIER President Chairman DR. JOHN G. ROGERS

Enc.

APPENDIX

HGSA POLICY ON HUMAN CLONING

The Human Genetics Society of Australasia (HGSA) represents the views of clinicians, counsellors, scientists and others who are professionally qualified in areas of human medical genetics. It includes most of those working in this field in Australia and New Zealand.

Since cloning of mammals has been shown to be possible, the HGSA notes that "human cloning" has received a great deal of publicity in the media, much of it negative. This is understandable in view of doubts about the ethics of human reproductive cloning, that is, cloning to produce a liveborn individual who shares a full genetic complement with a pre-existing child or adult donor of a somatic cell nuclear genome. Many people who support other forms of assisted reproduction such as IVF have ethical objections to reproductive cloning.

The HGSA has agreed on the following policy with respect to reproductive cloning and associated technologies as they apply to humans.

- There are no medical circumstances that would justify the use of reproductive cloning as defined above. This includes the risk of mitochondrial diseases, for which other reproductive strategies are possible and ethically preferable. The avoidance of serious inherited or sporadic disease, and the treatment of infertility, are legitimate objectives which would be better achieved using existing techniques that are acceptable to the profession and community and are already chosen by thousands of persons in Australia and New Zealand each year.
- 2. Reproductive cloning technology is ethically unacceptable because the scientific and medical consequences are currently unknown. It may be unsafe due to the accumulation of mutations in somatic cells during the life of the donor, which may pose serious health risks to the person cloned. The use of cloning technology in animal husbandry will allow this issue to be monitored during the coming decade.
- 3. Reproductive cloning technology is ethically unacceptable because it would reduce the autonomy of the child who has been cloned, particularly if the genome of the person cloned replicates that of an existing adult or child (intergenerational cloning) or if multiple clones are generated.
- 4. The HGSA favours a ban on human reproductive cloning in Australia and New Zealand because of the possibility of medical harm, and the desirability of maximising individual autonomy.

- 5. The HGSA recognises that the technology used for human reproductive cloning will lead to the development of technologies that have important medical uses. In particular, the creation of totipotent or pluripotent stem cells from somatic cells would markedly simplify transplantation procedures. As transplantation is presently limited both by immune rejection and by availability of tissue, this is an important clinical outcome that could bring great benefit.
- 6. The HGSA notes that at present the transformation of a somatic cell to a stem cell or totipotent cell may involve passage through a human embryo, which some think is unethical because it involves embryo destruction. There is a diversity of opinion within the HGSA, as within the community, on this issue. The HGSA believes that all embryo research should be carried out in accordance with National or State legal regulations in force, or in the absence of legislation, in accordance with NHMRC (Australia) or HRC (New Zealand) guidelines.

- 7. The HGSA strongly supports the development of technologies that allow the culture of human stem cells from somatic cells, and the isolation of growth factors that facilitate specific tissue development. We anticipate that in future, techniques will be developed which achieve totipotency without passage of somatic cells through human embryonic cells. Techniques may also be developed which permit the study of culture of a blastomere or blastocyst that is genetically incapable of implantation or development. We believe that research to achieve these aims should be encouraged provided that reproductive cloning does not occur.
- 8. The HGSA does not accept that cultured human cells can be equivalent of human embryos, far less human persons, even if the application of further complex technology might permit them to develop in such a way. Where existing Australian or New Zealand legislation could be so interpreted, it requires review.
- 9. There are important scientific questions that are relevant to research into human cancers, reproduction and ageing that can be answered using these technologies. None of these experiments involve human reproductive cloning as defined above.
- 10. The HGSA supports the creation of national statutory bodies in Australia and New Zealand to review all proposals and policies relating to the use of new reproductive technologies for human cell or tissue cloning in any context. These bodies should attempt to provide a mechanism to ensure that there is a uniform national and regional regulatory environment for research in this field across all States and Territories of Australia and New Zealand, and to ensure that this policy applies both to the public and private sectors.

Adopted September 1999