ANNEX I

REPORT BY THE FEEDBACK UNIT, MINISTRY OF COMMUNITY DEVELOPMENT AND SPORTS ON THE DIALOGUE SESSION ON ES CELL RESEARCH 8 DECEMBER 2001, 10.00 AM AT ORCHARD HOTEL

Present: Chairpersons

Mr S Iswaran Member, Feedback Supervisory Panel and MP

for West Coast GRC

Dr Jennifer Lee Member, Feedback Supervisory Panel and CEO,

Kandang Kerbau Womens' and Children's

Hospital

Presenters

Prof Ariff Bongso Research Professor and Scientific Director,

Assisted Reproductive Technology Programme, Dept of Obstetrics and Gynaecology, NUH

A/Prof John Elliott Member, Bioethics Advisory Committee

Participants

39 participants from all walks of life, including doctors, teachers, businessmen, lawyers, architects and undergraduates.

PRESENTATIONS

The dialogue session was preceded by two presentations: one by Prof Ariff Bongso on the science of embryonic stem cell research, and the other by A/P John Elliott on the social and ethnic issues associated with embryonic stem cell research.

DIALOGUE SESSION

The dialogue session was co-chaired by Mr S Iswaran and Dr Jennifer Lee, with A/P John Elliott on the panel. The views of the dialogue participants focused on the use of embryos for research, guidelines for ES cell research, reproductive cloning, regulations on human stem cell research, role of the Bioethics Advisory Committee and public education.

USE OF EMBRYOS FOR RESEARCH

- 3 (Consultant Architect & Planner) said that he was "neutral" on the embryonic stem cell research as he felt that research was "ethics-blind". While he felt that the research could better equip future generations to cope with challenges in life, he warned that it could also create a "nightmare" if it was not properly handled.
- 4 (Undergraduate) stated that she was for the research to go on but stressed that it must be accompanied by stringent regulations to ensure that there were no abuses, and that the researchers were doing it in a responsible way.
- (President, Investment Group) commented that the research would be acceptable if it was meant to seek cures for major illnesses such as cancer. However, it would become controversial should it be used for minor afflictions such as treatment of hair loss. AP Elliott said that in the hierarchy of possible benefits of the research, hair loss was far down the line.
- (Medical doctor) opined that human life began at conception. She viewed ES cells as a potential human being. She was concerned that the use of the embryos for research could lead to a dangerous road to fascist thinking, if we held the belief that some lives were valued less than others. She advocated for the use of adult stem cells in place of the embryonic stem cells, as she noted that there had been successful experiments done on mice with AS cells and there were studies at Harvard that treated thalassaemia and diabetes. She hoped that more research could be done on AS cells.
- (Doctor) shared his experience in research on AS cells. He described working with AS cells as an adult working with an abridged version of a children's story book. On the other hand, working with ES cells would be like working with the full text. He reiterated the greater potential and promise in the ES cell research. He noted that AS cells could only grow into certain kinds of tissues, while ES cells could develop into any kind of tissue and scientists believed they could make more advances using ES cells. In addition, ES cells were being used for testing of drugs for toxicity. New drugs which were currently given to very ill patients could be tested on ES cells. He recommended that researchers be allowed to work with ES cells before going on to AS cells.
- 8 (Doctor) felt that the trend towards the ES cell research was inevitable. If Singapore were to decide to outlaw the ES cell research, other countries like Indonesia or the US would continue with the research. If they eventually find a cure for major diseases like diabetes, would Singapore patients feel that they have been denied of the cure as a result of the law?
- 9 (Private Secretary) delivered a biblical story to advance his point that an embryo had a soul from the point of conception and hence should not be used for research.

- 10 (CEO) hoped that the ES cell research would help to prolong human life. He did not see any ethical objection to the use of excess cells, as they would be discarded anyway.
- 11 (Education Consultant) agreed with the need for ES cell research as he felt that it was pro-life and would improve life. He did not think that the research should be stopped just because of "the moot point that a cell is a life".
- 12 (Architect) felt that the 72 cell lines that was currently available from all over the world were insufficient, and that more centres and cell lines should be developed in order to benefit more people.

GUIDELINES FOR ES CELL RESEARCH

- 13 (Manager) felt that it was not ethical for the research to be commercialised. He opined that the research should be publicly funded and the findings should be used to benefit the masses.
- (Accountant) asked whether the 14-day cut-off time was a given. AP Elliott said that the 14-day cut off guideline was the benchmark used. Prior to 14 days, the nervous system of the embryo has not yet developed, and would hence feel no pain. Extraction and use of ES cells occurs at day 4 or 5. (Doctor) remarked that in the US, the guidelines stated the use of ES cells before 32 days, instead of 14 days.
- (Lawyer) felt that the reason he had difficulty with the 14-day cut off time was the rationale to justify the use of the cells. He felt that the crux of the issue was whether there is life in the cells or not, regardless of how mature they are. He asked whether it was morally right to experiment with a cell prior to 14 days just because it does not feel pain. Following this argument, he asked if one thought that a comatose patient was less human than a healthy person since he could not feel pain.
- 16 (Managing Director) asked whether a patient would be informed before he was given treatment using stem cells. Second, he wondered whether persons undergoing stem cell treatment would be made to disclose this fact to insurance companies.
- 17 (Theatre Director) stressed that research subjects should be fully informed of the full implications in order for them to "make educated choices". He added that while the issue of transparency in research was important, there was a need to ensure accountability.
- (Undergraduate) asked whether IVF patients were told about the fate of their excess embryos at the early stages of their treatment or was the choice to donate their cells for research came only after they had completed their treatment. Mr Iswaran noted her point that there would have to be, in principle, a difference between the decision for a couple to undergo IVF, and

the decision to donate excess embryos for research. In other words, there must be a de-coupling of the decision process and medical research personnel involved in these two stages to avoid any conflict of interest.

- 19 (Undergraduate) queried about the resource allocation of such treatment should it be successful. AP Elliott pointed out that the issue of resource allocation in medical treatment was not unique or particular only to treatment of disease by ES cells.
- 20 (Teacher) stressed the importance of knowing the source of the embryos. He also expressed concern that parthenogenesis could lead to women donating their eggs in exchange for money. He stressed that the aim of the research should not be profit-driven, but rather for the good of mankind.
- 21 (Merchant) said that he was concerned that the public was only hearing the positive side of the issue. He wondered what could be the consequences if human errors occur. AP Elliott commented that scientific research was a transparent process. It was not possible for researchers to hide any negative points as findings from reputable research institutions were made public.

REPRODUCTIVE CLONING

- 22 (Mr) said that he personally preferred the use of excess embryos from IVF procedures for research to those from therapeutic cloning, which was too close to the slippery slope of reproductive cloning.
- (Lawyer) said that he was against reproductive cloning. But he was concerned that if ES cell research were to be allowed, one would argue why therapeutic cloning and reproductive cloning could not be allowed. He also commented that this was the "same ethic with the Nazi experiment". (Education Consultant), however, felt that there was a need to move on and not be "so sensitive".
- 24 (Mr) asserted that should the BAC take the stand on no funding for reproductive cloning, it should not "go by the back door" and fund this research elsewhere either.
- 25 (Managing Director) felt that therapeutic cloning was alright but it should not move on to reproductive cloning.

REGULATIONS ON HUMAN STEM CELL RESEARCH

26 (Architect) felt that there was a need to have a regulatory body in Singapore. He pondered, however, how we could go about regulating researchers who conduct their research privately.

- 27 (Mr) was also concerned with control of technology and felt that there was a need to control underground research work.
- (CEO) felt that there would be difficulties in controlling the research. He pointed out that while companies dealing with drugs such as heroin were required to maintain accounts of storage and movement of these substances, heroin continued to be manufactured and circulated illegally. He felt that we should be realistic about how much we could control the human stem cell research.
- 29 (Doctor) opined that even with the best of regulations, enforcement of regulations was difficult. The situation might develop into a state where we have stockpiles of therapeutic clones and this would become a nightmare in disposing them. She also felt that there could be incompatibility and rejection of tissues by recipients.
- 30 (Doctor) felt that it was important that the government support ES cell research with public funds. He said that the furore in the US over President George Bush's recent announcement was that all the US government did was to limit public funding, which resulted in a flight of top talents to private companies. As long as the research is public funded, the process would remain transparent and could be easily regulated. Private funded research would be more interested in obtaining patents to make profits and would be difficult to track.

ROLE OF BAC

- 31 (Doctor) commented that he had heard a lot about the BAC but wondered what mechanisms were to take place, and had any regulations been put in place. AP Elliott clarified that the BAC was an advisory body tasked to examine the issues pertaining to the research held in Singapore and it would make recommendations to the Life Sciences Ministerial Committee.
- (Undergraduate) asked what would happen if there was disagreement on the human cell research. Mr Iswaran clarified that the objective of the session was to find out the tolerable limit among the public. If the research in embryos within 14 days was acceptable and should go on, then the next step was to ensure that this was done in a responsible manner, followed by the stipulations of the consequences of transgressions.
- (Head of Department) pondered whether, given that Singapore had already committed itself to the pursuit of the life sciences, research into ES cells was a given. Mr Iswaran said that research into ES cells was just but one facet of research in the life sciences, and that the BAC's position was still open.
- 34 (Teacher) said that as research was already going on, would the purpose of this discussion be on whether the research into such technology should go on or not, or rather regulatory issues for a field which had yet to be regulated in

Singapore. It was pointed out that the Singapore team of researchers in this field had been commended by the international research community as being very stringent in their adherence to regulations. As far as the BAC was concerned, it would advise the Government on the ethical issues and whether more regulations were needed.

PUBLIC EDUCATION

- 35 (Engineer) commented that Professor Bongso had delivered a good presentation which cleared a lot of misconceptions. But he felt that the general public also needed to be educated on this issue. He agreed with the BAC's position that specific religious stands should not be allowed to influence the policy. Otherwise, we would also need to rethink our laws on other issues like abortion and death penalty. (Mr) also agreed that BAC should not allow any religious viewpoints to dominate this debate.
- 36 (Retiree) stated that he was against ES cell research, despite, with tongue-incheek, that he stood to benefit from a hair loss cure. He hoped that there could be another session for the Chinese-educated, as they also needed to be educated on the issue and be given the opportunity to provide feedback. Their perspective could be different from that of the English-speaking group.
- (Principal, Primary School) shared that children's discourse on the matter were more pertaining to the uses of the research instead of the way the research is conducted. She pointed out that her students had painted a scenario where a society would be full of old people as people don't die, and no EM3 students as genes could be modified. Hence, she felt that children should be educated on the ethics of the bio-research while schools were giving more emphasis on life sciences.

CONCLUSION

Mr Iswaran thanked the participants on behalf of the BAC and the Feedback Unit for their frank feedback. He said that their views would be channeled to the relevant agencies for their consideration. The session ended at 1.25 pm, followed by a briefing to the media by the chairpersons.

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^{*} Please note that individual names in the above noted dialogue session have been removed in the interest of privacy.