Elton Humphery – Committee Secretary Community Affairs Committee Department of the Senate PO Box 6100 Parliament House CANBERRA ACT 2600

4 October 2006

Dear Mr Humphrey

Re: Legislative responses recommendations of the Lockhart review

I write as a member of the public. I am always concerned when legislation places ends before means.

I have read the legislation and am concerned at the deceptive use of terminology. It would appear that it must phrase the destruction of embryos in the past tense to dissociate this unpleasant necessity from the benefits of stem-cell research, and describe the use of aborted baby girls and their eggs in such obscure speech as to render the issue as an obscure cryptic crossword clue.

The research related to these bills seems to be insulated from comparative cost-benefit analysis by not asking the community how to designate billions of dollars exclusively for stem-cell work instead of other medical studies¹ but, leaving it in the hands of the NHRMC.

¹ In Stem cell research: a cautionary tale from California 8 September 2006 http://www.medfac.usyd.edu.au/news/features/2006/060329.php "the benefits of biotechnology were sold to the public in such a way that thousands … are now expecting miracle cures that simply won't eventuate, according to researcher Tamra Lysaght from the Faculty of Science…

[&]quot;Many politicians, scientists, capital investors, and other interested parties who spoke out did not declare their interests - to attract international prestige, to secure patents, to build business. None of this has anything to do with relieving people's suffering," argues Ms Lysaght, whose doctoral research is being taken under the auspices of an Australian Stem Cell Centre Premier Scholarship.

The expansive nature of the legislation, its lack of enforceable sanctions² and the bias of academics simultaneously acting as assessors, regulators and proponents is thus a major and obvious concern.

I wish to raise several other specific matters.

1. The first is in relation to the inherent media & scientific bias given to Embryonic Stem Cell Research.

I quote one of the many examples of the mainstream media trumpeting scientific "non-breakthroughs" involving embryonic stem cells while largely ignoring genuine breakthroughs with adult stem cells.

Last week, Dr. Robert Lanza of Advanced Cell Technologies published a report in the journal *Cloning and Stem Cells*, reporting that human embryonic stem cells had been used to partially restore vision in blinded rats. Not only was this not a new discovery - it previously being done in 2004 with ethical adult stem cells – but the initial breakthrough made very little news.

This same Dr. Lanza was recently involved in the hyping of a previous research in which he had claimed the use of embryonic stem cells without destroying embryos. The publishing journal *Nature* – to protect its reputation – subsequently pointed out he had destroyed every embryo he had used in that research. So why does the press unskeptically report this man again – as they did the previous report - when, it turns out, he has been misleading the press?

2. Business or Science?

In their report³, two of Australia's leading scientists try to put the case for what has improved since the last legislation was passed. If such 'opinion' was provided as the basis for a prospectus, I doubt the ACCC or ASX would approve it, indeed, it appears to identify a further risk that

² Ibid: "Rather than talking about restricting scientific research - "which is impossible since we don't have the infrastructure to police it" - we should consider what restrictions we should place on the technology, she says."

³ http://www.business.vic.gov.au/busvicwr/ assets/main/lib60041/sti_stemcell.pdf

needs to be assessed – the undue pressure on the acquiring of human ova. Here, commercial imperatives undermine ethical and scientific considerations as the 'a priori' issue. 4

3. Public Ignorance of Procedures

Despite the truly 'overwhelming' positive public support for eHSC⁵ , it is quite clear that the public – all 678 people over 14 years – probably have no concept of the difficulty, expense and low success rates of IVF, and would be oblivious to the fact of contributory social factors in relation to careers/lifestyle v. family and the fulfilled 'slippery slope' arguments of the early 1980's. The process of egg extraction is not a mere day procedure.

Whether the public (and patients) is getting good clinical outcomes, value for money or good public policy with IVF does not show up anywhere other than balance sheets of private clinicians.

4. The Alzheimer's Movie Men of Straw

Despite some media attention⁶, "little attention is given to the reality that none of the diseases most susceptible to stem-cell therapy touches more than 17 percent of Americans (by affecting them, a family member, or a close friend). But throw in Alzheimer's disease, and the number leaps to 28 percent. Seventy-two percent of respondents say they would be more likely "to support stem-cell research if you knew that experts think it may hold the key to curing the Alzheimer's disease that afflicted President Reagan⁷."

⁴ Ibid 1: Ms Lysaght is also concerned that no-one is talking about the women involved, the women who are supposed to donate their eggs. "Their interests are not being recognised. Should they be paid? If they are to be 'compensated' for their 'time and effort', does this mean that the eggs of professional working women will be more expensive than those of university students?"

⁵ http://www.roymorgan.com/news/polls/2006/4036/

⁶ http://www.theage.com.au/news/opinion/ignore-the-hype-in-the-cloning-debate/2006/09/03/1157222002193.html
"When politicians and politicised scientists make inflated claims about treating diseases such as Alzheimer's or motor neurone disease by stem cell transplant from cloned embryos, the groans from those engaged in neurological research are loud but largely unreported and politically unnoticed. The embryo hype obscures real scientific advances."

⁷ http://www.resultsforamerica.org/calendar/files/RstemcellresearchTopline.pdf

Similar appeals from the likes of Michael J. Fox are also at odds with the science ⁸ and more a case of the power of will, hope, and belief in the absence of evidence – the scientific criticism of faith based opponents to this research!

I thank the committee for the opportunity to put these thoughts to them.

Greg Briscoe-Hough

⁸ Ibid 1: People were told, for instance, that stem cell research would produce a cure for Alzheimer's, "but that's a whole-brain disease. We're not going to grow new brains,"