***FINRRAGE* Testimony to Senate Hearings on Legislative Responses to Lockhart Review**

Melbourne 24 October 2006

FINRRAGE – the Feminist International Network of Resistance to Reproductive and Genetic Engineering – welcomes the opportunity to address Members of the Senate Committee. We have been in existence since 1984. In the Australian context we have critically assessed the developments in reproductive technology and since the early 80s expressed our concerns about the dangers inherent in the IVF procedure. However, whilst it can be argued that a woman is exercising her reproductive choice in deciding to risk serious ill health or even death in her attempt to have a biological child, the matter of egg 'donation' – a misnomer as I will explain – for experiments including drug testing using embryonic stem cell research, shift this discussion to another level altogether.

What public debate on The Amendment Bills under discussion so far has almost entirely omitted to include is the simple fact that without egg cells from women one can not produce any embryos nor embryonic stem cells. Women's eggs - indeed huge numbers of them: in the thousands rather than the few eggs that are needed for an IVF cycle - are thus the indispensable 'raw material' without which none of these cloning procedures – the production of the SCNT embryo - can actually take place. So quite simply: no eggs, no embryonic stem cell research whether from an old-fashioned egg/sperm embryo or from a clone embryo derived from somatic cell nucleus transfer (SCNT). (Egg cells are also needed for research on parthenogenesis or egg fusion – not explicitly mentioned in this Bill but of scientific interest.)

I want to put an example to the Committee: What would you think of a business proposal that puts forward a multi- billion dollar idea for producing environmentally friendly tyres that have a much better safety record, are cheaper and can be disposed of not by burning but through a process that produces car fuel and absolutely zero green house gasses (in fact you can even get carbon credits for it!). Fantastic, great - just one little problem. The specific rubber plant necessary for these miracle tyres only grows in the Amazonian forest and the Indians guarding it have made it clear that they do not wish to part with it as this plant is part of their heritage. Hence it seems to me that for any serious venture capitalist the miracle tyre proposal is dead. Finito. End of that idea.

My question is, why has this not happened to the proposals of embryonic stem cell researchers who in our view have not even discussed where the thousands of eggs will be coming from? Is it so automatically assumed that somehow thousands of women will freely and altruistically provide them? For Dolly the sheep it took 277 eggs to produce one viable embryo; the disgraced Korean researcher Hwang reportedly used 2061 eggs from 129 women for his research (in Steinbrook, *N Engl J Med* 354:4, 2006) which later was found to be fraudulent and also exposed serious professional breaches of getting his junior female researchers to produce some of these eggs (and Korean women have lodged a number of law suits). Incidentally, the Lockhart review on which the Amendment Bill is based - relied on Hwang and colleagues' supposed production of human embryonic stem cell lines that is now disputed.

From an embryonic stem cell researcher's point of view I fully understand why they want the proposed changes to the law to allow them access to fresh egg cells rather than the frozen excess embryos from IVF programs so far permitted. Firstly, frozen material is always second rate – so even fresh embryos are preferable, and as for freezing extra eggs it has never properly worked to do with the egg yolk properties that do not like freezing. Secondly, women on IVF programs are usually older and they - or their partners - have chromosomal abnormalities: not good starting material for your foray into the unknown land of embryonic stem cell research. One can appreciate that an embryonic stem cell researcher's dream is petri dishes full of young freshly harvested egg cells from teenage women who have had very few divisions of their egg cells – get them young: they would be the best.

In order to understand what such an egg 'donation' entails I now briefly detail the process:

The Egg 'Donation' Procedure
After various blood checks and scan of ovaries, drug taking begins.

Please note that there are many drug combinations and times used in different clinics and they may also vary each time a woman undergoes egg 'harvesting' but here is one example:

1. A GnRH Agonist (that's a gonadotrophin releasing hormone such as Buserelin, Lucrin, Lupron) is given as nasal spray every 4 hours for approximately 14 days or administered as subcutaneous injections for up to 25 days. After an initial (potentially dangerous) flare up of egg cell growth through a LH surge (luteinizing hormone), it de-sensitizes the pituitary and stops egg cell growth. The idea is to shut down the 'normal' egg cell growth, turn off hormone production and block ovulation. Put differently, the GnRH Agonist puts the woman in a temporary chemical menopause.

2. Once the egg cell production has stopped, women are then given follicle stimulating hormones (FSH) such as Perganol, Metrodin HP, Gonal-F (the last two are genetically engineered). This process of stimulating egg cell growth - called ovarian hyperstimulation - leads to enlarged and painful ovaries and at times to the formation of cysts. In 5-10% of women it leads to ovarian hyperstimulation syndrome (OHSS): excessive fluid from painful ovaries is released into the abdomen, vomiting or extracting fluid causes dehydration and thickening of the blood. This may lead to serious thrombosis such as stroke and even death.

In order to avoid this, the woman needs to have daily or 2-daily scans – the aim is NOT to hyperstimulate too much but stimulate enough to get lots of near-to-mature egg cells ready for harvesting.

This is an important point as in women 'donating' eggs for research the main aim is to retrieve as many eggs as possible…so it might be tempting to perhaps administer a bit more FSH and wait a bit longer until starting the administration of hCG (human chorionic gonadotropin) and starting the egg retrieval procedure.

(Moderate to severe OHSS is treated in hospital with fluid administered intravenously; an older drug protocol which is still frequently used, combines Clomiphene and Pergonal before hCG injection. Clomiphene has a multitude of well documented mild as well as severe adverse effects.)

3. After all of this, the egg 'harvesting' starts. Following the administration of hCG (human chorionic gonadotrophin eg Profasi) 38 hours later the eggs are retrieved using a special vaginal ultrasound probe with an instrument attached to it so that the doctor can pierce the wall of the vagina, access the ovaries and retrieve the eggs. This is painful and may even require general anaesthesia.
Given the hormones involved the whole procedure leads to sometimes severe mood swings, water retention, and just plain feeling ill.

I now ask you - does this sound like an 'easy' and quick 'donation' that you/your partner – or your daughter(s) - would like to undergo? And how do you feel - as has been suggested - that young women who have a disease such as cystic fibrosis or juvenile diabetes - should be the ones asked to 'donate' these eggs? Or young women from families where a relative has a genetic disease should be altruistic and put their own health at risk?

Or must egg 'donation' be publicly acknowledged as a drawn out, painful and dangerous procedure with the possibility of not only short-term but also long-term adverse effects including ovarian, uterine or breast cancer and fertility problems. In other words, the preferably young 'donor' woman might jeopardize her own fertility and health.

FINRRAGE believes that this contravenes the principle that medicine should do no harm. We have thus joined an international group called Hands Off Our Ovaries (www.handsoffourovaries) and ask for a MORATORIUM on egg harvesting – and as a consequence – on embryonic stem cell research. Because, just to repeat it again:

No eggs, no embryos (SCNT or sperm/egg), no embryonic stem cells. In other words, without women there is no research cloning.

In addition we are also critical of some of the other Amendments in Senator Patterson's Bill such as Amendment 21 (on p. 10): to create via cytoplasmic transfer a human embryo that contains mitochondrial genetic material produced by more than 2 persons – that's actually 2 women. What it means is that in IVF an egg 'donor' has her egg yolk injected into an older woman's egg (or from a woman who has a genetic disease) because it is precisely the mitochondrial DNA in the egg yolk that enables the production of stem cells. In fact, we are puzzled about this Amendment: it seems that such research would benefit IVF treatment rather than stem cell research so with due respect, who is pushing this Bill? The convenient fact that many IVF clinics are linked to stem cell research centers?

Let me quickly add that *FINRRAGE's* objection to *embryonic* stem cell research does not mean the end to all stem cell research. Indeed only a small part of researchers focus on embryonic stem cells and as the Committee

would have heard, adult stem cell research is much less problematic.

In our Submission we detail other reasons for our opposition to this Bill. I will close by urging the Committee to remember the hype of the promises of Gene Therapy that abounded at the end of the 1980s. Exactly the same words (including threats to leave Australia!) are re-used in 2006 to conjure up the wondrous cures that embryonic stem cells will provide. Sadly, gene therapy never lived up to its promises and its image was severely damaged in 1999 when 18 year old Jesse Gelsinger died when he was a volunteer in a US gene research experiment (he was not seriously sick). How many women have to be rendered severely ill – or die – before our concerns are heeded? Further, gene therapy projects in France and in Germany were abandoned in 1999 and 2006 when patients undergoing these experimental therapies died (Gen-Ethischer Informationsdienst, 2006, p. 35). Why, in the wake of this stunning failure, should we yet again trust researchers' promise of embryonic stem-cell cures? *FINRRAGE* urges Committee Members as well as Members of Parliament not to sacrifice real live women's health to spurious utopian promises.

So Hands Off Our Ovaries. We urge you to reject the two proposed Amendment Bills.

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