FINRRAGE

Feminist International Network of Resistance to Reproductive and Genetic Engineering

Submission to the Scrutiny of Acts and Regulations Committee regarding the Infertility Treatment Amendment Bill 2007

Introduction
FINRRAGE (Australia) believes women will be severely hurt and exploited by the scientific procedures that would be allowed under this legislation. Women are central stakeholders in the Infertility Treatment Amendment Bill 2007 before the Victorian Parliament to allow cloning and the creation of embryos for research either through egg/sperm fusion or through somatic cell nucleus transfer (SCNT). It is the position of *FINRRAGE* (Australia) that this Bill would, if passed, have profound negative consequences for women who become egg 'donors.'

Right at the outset *FINRRAGE* (Australia) questions the decision to attach the Amendment Bill to the Infertility Treatment Act. Providing eggs for embryonic stem cell research does not bring any benefits to the egg provider as she is neither infertile, the partner of an infertile man, or indeed seeking to conceive a baby through IVF or related reproductive technologies. We therefore believe that the inclusion of this Amendment Bill in the Infertility Treatment Act should be reason enough to reject the Bill for technical and legal reasons - even before considering ethical and human rights issues as grounds for rejection.

FINRRAGE (Australia) acknowledges that compassion and concern for people suffering from disease and injury is motivating many politicians to positively consider this legislation. However, we strongly believe that women's lives and bodies should not be invaded for the 'public good', and that women's health and future fertility must not be compromised by experimental research with no proven benefits for these 'donor' women or their families - or anyone else except perhaps in the future for pharmaceutical and biotech companies.

We believe that such harm done to women amounts to a breach of women's human rights to bodily integrity: women must not be used as experimental objects in research that is of no benefit to them.

We urge you to consider the serious concerns that have been raised by women's groups all over the world (eg by Hands Off Our Ovaries, www.handsoffourovaries.com), as well as by scientists and ethicists in some of the world's most respected medical journals, and reject the proposed Infertility Treatment Amendment Bill 2007. *FINRRAGE* (Australia), as a member of Hands Off Our Ovaries, demands a world wide moratorium on egg harvesting for research purposes.

Before we provide more details on why we ask Members of the Victorian Parliament to reject this Bill, we list two main points that are central to our position:

1. We believe that medicine must always be guided by the principle of 'do no harm'. The harvesting of multiple eggs from healthy women's bodies after the administration of dangerous drugs for the creation of research embryos (to later extract stem cells) has a high probability of causing short- and long-term health problems including cancer and loss of fertility. These procedures harm women without providing any benefits for them. This is unacceptable and unethical practice. It is a breach of women's human rights.

2. The language used by promoters of stem cell research is confusing and dishonest.
Terms such as 'therapeutic cloning' and 'somatic cell nucleus transfer' (SCNT) are highly confusing. Firstly, there are no 'therapies' for the women whose eggs constitute the *necessary* raw materials for research cloning. The terms used should always be *cloning* or *research cloning*.

Secondly, we have heard recent comments from stem cell researchers who say that the woman's enucleated

egg cell into which the nucleus from another person's cell is inserted does not constitute a 'proper' embryo. They say this because there is no sperm involved and, in so doing, hope to win the support of people who are against the Infertility Treatment Amendment Bill 2007 because of their (religiously motivated) respect for human embryos. This position is dishonest because it not only disguises the fact that the egg harvesting procedure for women remains the same, but also because this somatic cell nuclear transfer (SCNT) is exactly the technique that created Dolly the sheep and other cloned animals (and in theory can create a cloned human being). It is, quite simply, the technique of *cloning* and must be named as such.

In addition, to say that a SNCT embryo is no 'proper' embryo because it lacks a sperm is also deeply offensive to women as it is nothing short of re-creating the theory of 'woman-as-vessel' in the tradition of the Greek dramatist Aeschylus as well as philosopher Aristotle's creation of the Homunculus (the woman-free man).

In 2006, such women-disparaging language can not be tolerated. We urge all Members of Parliament who respect embryos to equally respect a SNCT embryo and as a consequence respect the dignity and bodily integrity of women who *must* provide the egg cells so that these research embryos can be created in the first place. **No eggs, no embryos (SNCT or sperm/egg), no embryonic stem cells. In other words, without women's eggs there is no research cloning.**

***FINRRAGE* (Australia) urges Members of the Scrutiny of Acts and Regulations Committee as well as all Victorian Parliamentarians not to sacrifice real live women's health to spurious utopian promises.**

Furthermore, embryonic stem cells constitute only a minor part in the overall research efforts of stem cell researchers. Stem cells - young and adult - can be found all throughout the body including in many organs. These cells are extracted and used in many experiments (eg recently from teeth and eyes). The (hysterical) notion put out to the public that only embryonic stem cells can be used for stem cell research projects (including the testing of drugs) and that without them all research will be stopped lacks any scientific and factual basis.

We now provide more details for our suggested rejection of the Infertility Treatment Amendment Bill 2007 - should it indeed be considered by Victorian Parliamentarians and not deemed legally inadmissible because of its inclusion in the Infertility Treatment Act when clearly the woman providing the eggs is not undergoing infertility treatment.

The scientific imperative

The scientific imperative is driving the current push for creating and using cloned human embryos for research. It has proved very difficult to argue in public debate on the necessity for cloned human embryos and embryonic stem cells that the interests of *women* override the possibility of 'cures' to be perhaps in the far future developed by scientists. This imperative is manufacturing hopes in the public mind for miracle cures from embryonic stem cells. It also manufactures the idea that without human embryos (hence women's eggs) there can not be any stem cell research. Feminist concerns about the concrete reality of the health of Australian women is brushed aside in favour of such visions of cures - and big time profits and glory for the stem cell industry (and the Victorian State's Treasury and Melbourne's reputation as the 'biotech capital' of Australia.

In fact, there is no such thing as 'therapeutic cloning' - because for the female egg 'donors' there are no therapies. The phrase 'therapeutic cloning' is itself deceptive because it suggests that there are immediate, established benefits. As we hope all Parliamentarians are aware, there are none such benefits as yet, even in animal studies. **Human embryonic stem cells have not been created anywhere in the world.**

We also take issue with the proposed use of women's egg cells to create animal- human blastocysts. Women's genetic material has been discarded by removing the cell nucleus with its chromosomes (this act in itself is highly charged!), but the maternal mitochondrial DNA in the egg cytoplasm remains and is indeed *essential* to deliver the energy to start stem cell development. *FINRRAGE* (Australia) believes that it is ethically questionable to manufacture such hybrids even if - or perhaps precisely because - they will mainly be used for drug testing. Maternal mitochondrial DNA has an important place in evolutionary biology and in our view should not be 'played around' with (see Bryan Sykes *The Seven Daughters of Eve,* 2001, in which he traces the ancestry of Europeans through maternal mitochondrial DNA). Similarly we do not support the use of enucleated animal eggs (eg hamsters or rabbits) that are combined with the cell nucleus from a human being.

The current debate reveals a demeaning and commercialising attitude towards women's eggs, bodies and indeed existence. Ethicist Julian Savulescu wrote in 2005 that since women have so many eggs and will have

so few children (and the women who had eggs removed weren't planning to get pregnant at the time) there is no problem with removing and using them, and in fact we *ought* to proceed with such research. He describes a moral imperative to make use of 'spare' biological material, since the women weren't going to get pregnant, and maintained that the research was 'very important'. He considers women's eggs to be 'spare' even whilst inside a living woman's body (Savulescu, 2005)!

Cloning/embryonic stem cell research also has special implications for the way people with disabilities are perceived and treated. One disability commentator (Leipoldt, 2002) says that until the current embryonic stem cell debate he thought there had been

> … some understanding that disability is not just created through impairment. Our collective social values and attitudes create much of the disability experience … Now, the embryonic stem cell lobby is shamelessly sacrificing these hard-won gains for profit, reminiscent of tear-jerk fundraising by charities of old. We're back to 'disability as tragedy', a condition to be pitied and cured ... I found it offensive to see disability being used as a lobbying tool for the biotech industry.

To justify the research goals, women as well as all people with disabilities are sometimes held up as future beneficiaries of this research. But the debate is driven by the immediate beneficiaries, the research and biotechnology communities, which are determined that this research go ahead. The science lobbyists are intolerant of voices from other communities and in some cases have misled Parliamentarians in their determination to get their way, as we saw with the infamous walking rat on Professor Alan Trounson's laptop in 2002.

The recent fraudulent research by Korean scientist Hwang Woo-suk (2004) has seriously and rightfully damaged public trust in those advocating cloning research. In fact *FINRRAGE* (Australia) finds it amazing that after the revelation of Hwang's fraud including exorbitant use of egg cells to conjure up his stem cell lines that proved not to be real, and the way he procured them from his junior female researchers, anyone in the world would suggest that this wasteful way of using eggs extracted from women after dangerous and painful procedures would be an ethical way to conduct research. To us it is proof that women's lives - and wellbeing - continue to count for very little.

Women's bodies as objects for research and profit

The language of some researchers implies that researchers see women as experimental test sites, or as Robyn Rowland called it *Living Laboratories* (1992). Women are described by IVF researchers as 'endocrinological environments', 'therapeutic modalities', 'egg crops' and 'alternative reproductive vehicles'. 'The aim of the treatment is to reimpose a normal rhythm over a disordered one, to recover virgin soil', said one researcher (in Klein, 1989).

Women's bodies are central to the hopes and aspirations of scientists determined to work in cloning and human embryonic stem cell research. Without access to women's bodies to harvest their egg cells, scientists are not able to produce any embryos or use so-called 'surplus' embryos from IVF.

But women's eggs don't drop from heaven. They come from a woman's ovary, which is located *in* a woman's body.

To 'donate' eggs, women are first put into chemical menopause and then given strong doses of drugs to hyper-stimulate their ovaries into producing many more eggs than the usual one per natural cycle (or 5 to 10 in an average IVF cycle). The matured eggs are retrieved by a needle inserted through the vagina, guided by ultrasound, in a surgical procedure requiring anaesthetic which carries serious risks. Additional risks are involved, the most important being ovarian hyperstimulation syndrome (OHSS). Up to 10 per cent of women who donate egg cells experience this serious condition, which can lead to hospitalisation, renal failure, future infertility and even death (Magnus and Cho, 2005).

Furthermore, mild forms of OHSS occur in 10-20 per cent of cycles - this is in fact encouraged as it leads to the maturation of a larger number of egg cells - with symptoms including nausea, vomiting, diarrhoea, and abdominal distension. Other serious complications can include rapid weight gain, fluid accumulating between tissues and organs in the pleural and abdominal cavity, and respiratory difficulty. Women may require hospitalisation. There have been reports of thromboembolism, renal failure, adult respiratory distress, and haemorrhage from ovarian rupture. By August 2006, six UK women egg 'donors' were known to have died of OHSS (in Beeson and Lippman, 2006). (Many more women have died since the beginning of IVF research at the end of the 1970s, see Klein 1989).

These serious health risks are not surprising considering that superovulation drugs can stimulate women's ovaries to produce up to 30 eggs a month instead of the usual one in a natural cycle (Stevens, 2002).

Animal studies also suggest an increased risk of ovarian cancer in later life after multiple cycles of hyperstimulation (Steinbrook, 2006). No systematic research has been conducted as IVF clinics are not keen to invest money in finding out whether their services cause cancer. Since the 1980s *FINRRAGE* has warned against danger from fertility drugs (eg clomiphene citrate and Pergonal , see Klein/Rowland, 1988) and asked for research to monitor women's health after IVF treatments - to no avail. But the deaths accumulate – now even for women who do not engage in ovarian stimulation in order to get a test-tube baby, but simply 'donate' egg for research cloning.

In August 2006, a healthy 37-year-old UK woman died from internal bleeding and renal failure after egg harvesting for IVF. This follows another UK woman, a healthy 33-year-old, who died during the same procedure last year. Medical staff rushed to defend their IVF programme and to reassure women that the procedures were safe, saying that deaths are rare and that a woman is more likely to die from childbirth than IVF (Henderson, 2006). This is a disingenuous attempt to preserve the reputation of their business; few women who undergo IVF actually deliver a baby (the 'success' rate is still only about 25 per cent). And for women 'donating' eggs for research, the comparison with childbirth is meaningless.

There are substantial risks to women using fertility drugs. To defend these drugs, some may argue that women in IVF programmes accept them routinely. But Klein (1989) interviewed forty Australian women who left IVF without a child. They suffered ovarian cysts, enlarged ovaries, ovarian abscess and septicaemia, constant bleeding, dizziness, nausea and generally felt 'very ill'. These women hoped for a child but didn't get one. Women 'donating' eggs for research will receive no benefit at all - and it's quite possibly that no-one else will either.

Concerns about informed consent

There are serious ethical issues surrounding informed consent for women 'donating' eggs for research. Consent for egg 'donation' is a two-part process, write Magnus and Cho in *Science* (2005). Firstly, women will need to consent to the risks and benefits of the procedure. Then they will need to consent, as tissue donors, to the proposed use of their eggs. Magnus and Cho write that

> … the clinical consent model does not seem to fit women who agree to donate oocytes entirely for research purposes. These women are not pursuing the procedure for any reproductive or medical benefit to themselves; rather, they are exposing themselves to risk entirely for the benefit of others. If we were to think of them as simply clinical patients, their physician's fiduciary obligations would seem to require counsel against undergoing such a procedure for no benefit (Magnus and Cho, 2005).

Magnus and Cho (2005) also note that Korean scientists Hwang Woo-suk's informed consent process focused on the research rather than the procedure; in other words, it was a focus on the potential 'good' of science in general rather than on the wellbeing of the 'donor' woman herself. Many cloning advocates are taking exactly the same perspective. If they were to follow Julian Savulescu's reasoning (2005), it will eventually be considered morally wrong *not* to donate 'spare' eggs cells for research, and consent may become even less important.

Who has the power?

Many commentators, even women, have been dismissive of the risks that women are asked to bear for the sake of research cloning. As with all reproductive technologies, women are exposed to far greater risks than men. Many seem to believe that the risks to women are solved by informed consent requirements and the banning of inducement.

FINRRAGE (Australia) wishes to point out that although women may not be physically forced to 'donate' eggs, women's decisions take place in particular social contexts in which there are often significant imbalances in power between women and a) the researchers who want embryos to pursue their research; and, b) the companies looking to cash in on a biotechnology investment that may be worth millions, especially when they can 'patent' the products from women's eggs (and, in the case that stem cell cures ever eventuated, could then sell back their medical services to the providers of the raw materials – the egg 'donors'!).

But many women would feel obliged to undergo the dangerous egg harvesting procedure because they want to help develop therapies for family members or friends. Magnus and Cho (2005) write that such women are

more likely to be vulnerable to coerced donation than 'altruistic strangers'.

Indeed we argue that cloning legislation exploits women by encouraging them to be 'altruistic'. They will be applauded for being 'generous' by providing their eggs. With a focus on the promised 'cures' for all kinds of diseases - and therefore the focus *not* on women's health - women distressed by the suffering of a loved one will be especially likely to be convinced by enthusiastic scientists to 'donate'. The woman and her family, friends and community will receive no benefit whatsoever - just ill health and possibly death.

Under the proposed Victorian legislation monetary incentives will be banned. But for any eggs to be available, there will necessarily be some motivation to encourage women to 'donate'. Reimbursement of women's 'expenses' or 'inconvenience' for 'donating' ova may not seem profitable to the people considering this legislation, but it can represent a substantial sum of money to poorer women, particularly students and unskilled or unemployed women. These are women who may not otherwise be able to earn extra money in any other way.

Professors Diane Beeson and Abby Lippman (2006) write that young women at US universities have been especially vulnerable to paid egg 'donation', because of massive education-related debt. Recent changes to Australian higher education, and rising debt levels amongst young Australians, suggest that Australian women will similarly be attracted to literally selling their bodies in order to fund their education or their mortgage. This would add 'reproductive' prostitution to the actual prostitution some university students already engage in to make ends meet.

The National Academies recommended in 2005 that no payments should be provided for egg 'donations', partly because of the uncertainty about the actual risks of severe complications (Steinbrook, 2006). But some scientists and bioethicists argue that it is wrong to *not* pay women to 'donate' eggs. In the case of substantial payments for 'donating', there is no doubt that poor women would bear the greatest physical burden for cloning research.

Hwang Woo-suk, the disgraced Korean scientist, used egg cells from junior assistants in his laboratory as well as paid donors. He admitted to lying about how he obtained the eggs. Ongoing investigations are suggesting that dozens more donors, and hundreds more eggs, were used and never reported. And, since the experiment failed and the researcher was fraudulent, the situation 'represented a betrayal of trust between scientists and research subjects' (Steinbrook, 2006).

Hwang's research formed the centrepiece of the Lockhart Committee's report which recommended that cloning research proceed in Australia. That the research was later found to be fabricated seems to have made no difference to embryonic research cloning advocates. It also seems to make no difference, at least to cloning advocates, that Hwang lied about how many women 'donated', how many eggs were harvested, and how consent was obtained. *FINRRAGE* is concerned that 'cowboy cloners' (a phrase coined by Suzi Leather, former chairperson of the HFEA in the UK) won't let a woman's health get in the way of their career. Frankly, as said earlier, *FINRRAGE* (Australia) is astonished that such research can even still be considered when it has become so clear that women are exploited.

A coalition of 35 women's groups is now reportedly suing the South Korean government, representing the women who were harmed in the process of harvesting eggs for the fraudulent and failed research (in Beeson and Lippman, 2006).

Hwang brought shame upon himself by coercing egg 'donation' from his laboratory junior women, and by illegally buying more eggs. Given the demonstrated difficulties recruiting altruistic 'donors', it is reasonable to assume that eventually Australian scientists will seek other ways to obtain eggs. They might seek for another change to the law, allowing for payment, or preferential or discounted IVF treatment – as is already happening in the UK. More frighteningly, they might tap into the established international egg trade.

A British journalist spent weeks investigating the underground trade in women's eggs, which she traced to poor Eastern European countries. As she wrote in *The Daily Mail* (2006), including this story about poor women who 'donated' eggs:

> Too often, those women are left damaged by the procedures they undergo - and a growing number have been robbed, as a result, of the chance to have families of their own.

They include women such as Alina Ionescu from Romania, whom I met in the grim post-communist centre of Bucharest.

In so many ways, Alina is just like any young bride. At just 20 years old and married for nine months, she dreams of a future in which she and her husband, Nicu, will watch their children grow.

But Alina may never have children. Two years ago, when she was saving to get married, a friend told her of an easy way to make money - she could donate her eggs at one of the many Eastern European clinics to which British women travel for fertility treatment.

The doctors at the Romanian clinic where Alina was paid £150 for her eggs - a clinic which had links with a leading London fertility centre - left her ovaries so damaged and scarred that she is now infertile.

Alina says 'the doctor who did this to me - I would like to tell her she ruined my life. She should have told me what might happen.'

Cloning demands extensive use of women's bodies

In order to develop and then provide the promised therapies for thousands of people, many more hundreds of thousands of eggs would be required and they would become commodities (see Kolata, 1998). From the point of view of embryonic stem cell researchers, there is clearly a serious shortage of human eggs (Check, 2006).

Carina Dennis writes in *Nature* (2006) that

> … cloning is a wildly inefficient process, often requiring hundred of eggs to produce a single viable clone. Indeed, one of the shocking revelations of the Hwang affair was the sheer number of eggs his lab had got through.

At first, other researchers were surprised that Hwang had managed to get 242 eggs from 16 volunteers (Cyranoski, 2004). Eventually it transpired that he had used an incredible 2061 eggs taken from 169 women (Steinbrook, 2006).

Robert Lanza, of Advanced Cell Technology, believes that there will not be enough eggs for the research and that scientists will need to develop other methods. Given some Australian politicians' and scientists' unrestrained enthusiasm for cloning, it is reasonable to suspect that within a few years Federal as well as the Victorian (and other States') Parliaments will be asked to consider allowing eggs to be collected in ways other than altruistic 'donation' - perhaps with large financial incentives (as in the US where egg 'donors' get paid thousands of dollars), discounted or preferential IVF treatment (as in the UK), or perhaps from ovarian biopsies or aborted female foetuses, the ultimate in informed consent violations.

Conclusion

FINRRAGE (Australia) concludes that the short-term risks of the egg harvesting procedures and drugs involved are well-documented, including some women's deaths. That the long-term risks cannot be conclusively proven is due to the scandalous omission by research establishments internationally to conduct systematic, comprehensive follow-up of women's health since the commercial advent of reproductive technologies in the early 1980s. Studies on long-term effects are still not done and because so many different drug cocktails have been used, we doubt that it will ever be possible to conclusively prove which drug or drugs caused - and cause - the cancers. In Australia, in 1995 the NHMRC published a report *Long-term effects on women from assisted conception*. Marcia O'Keefe and *FINRRAGE* member Renate Klein were members of the Working Party. (Marcia O'Keefe has since died of breast cancer which in her view - and she wrote about it (O'Keefe, 1992) - was due to an IVF treatment.) O'Keefe and Klein managed to get in some recommendations for research on long-term effects from IVF. 12 years later, to our knowledge no such studies have been undertaken which we find breathtakingly scandalous. Nevertheless, even without the systematic long-term research there is substantial worldwide 'anecdotal' evidence and as time goes by it is mounting. We suggest that both short- and long-term risks are unacceptable when the research is speculative, inefficient, and of no benefit to the woman 'donating' her body parts.

Twenty-five years ago men controlled childbirth and women's health care. Today they also control conception. Julian Savulescu writes that Australia has a moral obligation to pursue this research (Savulescu, 2005). Will

Australian researchers eventually want on-demand access to women's bodies to harvest eggs for the 'public good'? 'Altruistic' commodification is commodification all the same!

International experience shows clearly that women are being exploited and harmed for research with absolutely no proven benefits. Cloning research will be conducted at the expense of women's health and lives.

For all these reasons, we urge Members of the Scrutiny of Acts and Regulations Committee and all Victorian parliamentarians to reject the Infertility Treatment Amendment Bill 2007. Neither women or their eggs or their embryos should be plundered and have their human rights abused in the interests of medical research with questionable outcomes - and no benefits to themselves.

FINRRAGE (Australia) joins with the international coalition, *Hands Off Our Ovaries*, and calls for a moratorium on egg harvesting for research. To protect women's health, Australia should follow the lead of 30 countries who prohibit research cloning* and ban egg harvesting. We urge Members of the Scrutiny of Acts and Regulations Committee as well as all Parliamentarians to join the Hands Off Our Ovaries Coalition and say 'no' to the abuse of women's bodies and women's dignity.

Renate Klein and Belinda Morris
11 April 2006

* These countries include Argentina, Austria, Brazil, Canada, Denmark, Finland, France, Germany, Iceland, Italy, Japan, Netherlands, New Zealand, Norway, Peru, South Africa, Spain, Vietnam (see www.glphr.org/genetic.htm for further details).

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