

# **Transforming ‘Waste’ into ‘Resource’: From Women’s Eggs to Economics for Women**

presentation by Sarah Sexton, The Corner House, UK at

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“If we are worried about people entering into ‘desperate exchanges’ – poor people selling their kidneys – we are worried about maldistribution of wealth as well as commodification in the abstract.

“If we are worried that kidney-sellers will be disproportionately poor people of color, then we are worried about wrongful racial subordination as well.

“If we are worried about poor women selling their babies, then we may be worried about maldistribution of wealth and wrongful gender subordination as well as commodification in the abstract.”<sup>1</sup>

## **Regeneration or Regression?**

What has prompted some of us to revisit this topic “Commodification and Commercialisation of Women's Bodies” in recent months is not so much “*reproductive technologies*”, such as in-vitro fertilisation (IVF), but those would-be technologies that, it is claimed, will in future treat diseases, conditions or injuries that cannot at present be cured or even treated:<sup>2</sup> nothing to do with reproduction.

Human embryonic stem cells are considered vital by some scientists and policymakers to this new field of “regenerative medicine”. Embryos created in the laboratory but not inserted into a woman's uterus during IVF – a reproductive technology – have been vital to obtaining embryonic stem cells. Thus “disease treating” technologies are, in fact, closely intertwined with reproductive technologies after all.

Embryonic stem cells have the (theoretical) potential to develop into any other cell type within the body (blood, muscle, nerve, and so on) and can reproduce themselves indefinitely by dividing. Human embryos have been created in the laboratory since the early 1970s (the world's first IVF baby, Louise Brown, was born in the UK in 1978), enabling research to be carried out on them.<sup>3</sup> But it was not until some 20 years later, in 1998, that the first human embryonic stem cells were isolated and cultured in the laboratory from human embryos “left over” or going to “waste” after IVF

procedures.<sup>4</sup> With this development, “surplus” embryos accelerated their transformation from “waste” to “resource”.<sup>5</sup> Can these stem cells be made to turn into a certain type of body cell that could be inserted into people whose own body cells are not functioning as they should? Pancreas cells for diabetics? Brain cells to repair the ravages of neurodegenerative diseases such as Parkinson's? Nerve cells for those with spinal cord injuries? Heart muscle cells injected to shore up failing heart tissue?

The potential obstacles to such “regeneration” are significant. Is it certain that the cells inserted into a heart, for instance, will not develop into those of another body organ or tissue as well, a liver, nerve or muscle, for example? Will the cells keep on and on and on dividing . . . and thereby create tumours?<sup>6</sup> Or will the cells simply die to no effect at all? Will the sick person's immune system reject these transplanted cells?

Some researchers believe that one potential way of overcoming this last obstacle, immune rejection, is to employ the cloning technology that led to the birth in Scotland in July 1996 of Dolly the sheep, the first mammal cloned from an adult cell.<sup>7</sup> The idea would be to take a cell from an adult with an incurable disease or injury; put its nucleus into a human egg<sup>8</sup> whose own nucleus has been removed; and stimulate by means of a jolt of electricity the combination to start cell division like an embryo. Then the outer layer of this created embryo would be dissolved at about the 140 cell stage so as to extract the embryonic stem cells, which would (somehow) be directed to develop into the required body cells. These cells could then be inserted into the sick person to repair diseased or damaged tissues – all (theoretically) without the risk of immune rejection because the genetic material would have come from the sick person in the first place.

The idea began to seem feasible in February 2004 when a team in South Korea led by Dr. Hwang Woo Suk of Seoul National University announced that it had created cloned human embryos from which it extracted embryonic stem cells.<sup>9</sup> Regeneration seemed to come yet one step closer a year later when the same team announced in May 2005 that it had extracted embryonic stem cells from human embryos cloned from the adult cells of people with untreatable conditions.<sup>10</sup> But when could such personalised transplants become a realistic possibility? Depending on whom you believe, either within the next few years – or never, because of a multitude of practical and biological difficulties.<sup>11</sup>

One key practical difficulty hampering human cloning research and any future clinical treatments involves human eggs. Where are they all coming to come from – or rather from whom? As human embryo cloning research seems to continue apace in the United States, Britain, South Korea, China and Singapore, it is this “difficulty” of “the missing women”<sup>12</sup> that has renewed feminist concern about the further commodification and commercialisation of women's bodies. And it is this difficulty that has invariably been left out of commentaries on using human cloning research to treat sick people ever since Dolly the cloned sheep was born nearly a decade ago,

Today, I aim to look briefly at how women’s eggs have been obtained for IVF and for cloning research; to describe different attitudes towards paying women to undergo egg extraction so as to get more of them; and to analyse who is paying for cloning research and why to see whether these considerations can inform strategies for intervention to resist the further commodification and commercialisation of ourselves.

## A “Shortage” of Eggs

Some women cannot become pregnant or give birth because there is some problem with their eggs – they are too old, they are damaged, they are unviable. But if another woman, preferably under the age of 35, “donates”<sup>13</sup> an egg, it may be possible for such women to have a child.<sup>14</sup> As with body organs, however, there are not enough donated eggs available for the women who would like them.<sup>15</sup> In the UK, 90% of the 85 fertility clinics report an “egg shortage”.<sup>16</sup> Women do not seem prepared to go through an uncomfortable, time-consuming and invasive egg retrieval procedure that can be potentially health and life-threatening<sup>17</sup> – and this is even *before* they've been informed that this is what egg extraction involves – unless they hope to become pregnant themselves by means of IVF.

How can more women be persuaded to provide their eggs for other women to have a child? Many debates about this egg shortage discuss the pros and cons of altruism – donating freely and voluntarily to help others – versus payment – selling your eggs.

The United States allows women to be compensated financially for providing their eggs as long as payments do not constitute “undue influence” on them. The going rate is between \$4-7,000 for one extraction (3,200-5,600 Euros), but some would-be parents are prepared to pay around \$20,000 for the eggs of a student at an elite university, and even ten times this amount for those of a supermodel.<sup>18</sup> Women or couples in the US cannot be paid, however, for donating their leftover embryos to other couples or for research, because this might encourage them to go through the whole process just for the money.

In contrast, the UK has long maintained more of a culture of free, voluntary, altruistic donation – the gift relationship<sup>19</sup> – for body parts and tissues in general in which the donor is not paid in cash or kind, and does not gain any benefit for themselves.<sup>20</sup> Eggs and sperm have been treated slightly differently; nonetheless, the top legal limit for payment for both is £15 (22 Euros) – gender equality here at least<sup>21</sup> – plus “reasonable expenses”.<sup>22</sup>

The assumption that people are willing to donate gametes (eggs and sperm) for altruistic reasons was implicitly challenged in the UK in 2000 when fertility clinics were allowed to reduce the fees they charged, sometimes by as much as half, to a woman undergoing IVF, or even to provide the treatment at no charge at all, if the woman donated some of her eggs to other women who wanted to have a baby.

Fertility treatment is generally provided on a commercial basis in the UK. The high costs of IVF make such egg sharing an attractive option for those who don't have much spare cash. One cycle of IVF costs about £2,000-£4,000 (3,000-6,000 Euros); the drugs can cost an additional £1,000 (1,500 Euros), and on top of this are the expenses of consultation, tests and embryo freezing – and it can take several cycles of IVF before a woman becomes pregnant. Most IVF treatments are paid for by individuals themselves; the public purse pays for just one-quarter of treatments. The majority of IVF takes place in private clinics.

In 2004, however, the public body that licenses and regulates most aspects of IVF and embryo research, the Human Fertilisation and Embryology Authority (HFEA), decided to review the question of payment. Between November 2004 and February 2005, it held a public consultation on “Sperm, egg and embryo donation” or SEED

(appropriately enough) for short. The results will be announced in October 2005, but the HFEA itself has already suggested that the £15 limit for eggs and sperm should be increased at least to £500 (730 Euros) but not beyond £1,000 (1,500 Euros).<sup>23</sup>

### **At Home and Abroad**

Because of the shortage of eggs within the UK (and because of the high costs and some legal restrictions), some women and their male partners (or just a man's sperm) travel to other places to buy “donated” eggs in order to become pregnant – Spain, Crete, the US and Romania have been favoured destinations.<sup>24</sup>

“We have to ask why there appear to be so many more altruistic donors in other countries,” said a spokesperson from the HFEA last year, talking about IVF clinics in Romania and Crete where women provide eggs for UK couples.<sup>25</sup>

Does “altruism” explain why the GlobalART clinic in Bucharest (since closed down) had 300 women on its books prepared to provide their eggs to childless couples in the UK and United States?<sup>26</sup> Their willingness to do so wouldn't have anything to do with the fact that the women were paid some 100 to 250 Euros for their “reasonable expenses”, more than one month's average income in Romania – or would it? And incidentally, I guess it must be “altruism”, too, that explains why the numbers of Eastern European women and children being trafficked to Western Europe to work in the sex and other industries have gone up dramatically in the past decade.

The US company, GlobalARTusa, to which the Romanian clinic was affiliated, is an egg broker. It attributes the success of its egg “donation” programme not to Romanian altruism, but to “our international source for high quality Oocyte (egg) donations *at exceptional prices*” (emphasis added).

It charges would-be mothers \$8,000 (6,400 Euros) for the eggs – remember that the Romanian women providing them were paid a maximum of 250 Euros. “This large price advantage” over the cost of obtaining donor eggs within the US, says GlobalARTusa, is nevertheless compatible with European donors being “remunerated very well by European standards, where the cost of living is lower than that in the United States”.<sup>27</sup>

GlobalART apologises on its website that its egg donors are “generally of Eastern European Caucasian ancestry”, and thus it is not a reliable source of eggs from black or Asian donors. Given that infertility affects women of colour more than white women (largely because of poverty and racism), but that those buying IVF are largely white with financial resources – who else not only has the money but has long been considered “legitimate” mothers and families? – such a statement not only seems superfluous but smacks of “political correctness” as well.<sup>28</sup>

### **Cloning Increases “Shortage”**

Cloning research has only intensified prospecting for human eggs, preferably from young, healthy women, and intensified debates about whether women should be paid to provide them. Given the commercial context of IVF and, I would argue, of embryo

research itself, it's perhaps not surprising, although perhaps ironically encouraging, that the ethics board of the US cloning company, Advanced Cell Technology (ACT), has reportedly said: "If you don't pay [the women] anything, it's exploitation, and if you pay too much, it's coercion".<sup>29</sup>

In the US, the Bedford Stem Cell Research Foundation, founded in 1996, has had an egg donation program specifically for research, not for IVF, since 2002.<sup>30</sup> The eggs went to the firm, ACT to carry out cloning and stem cell research.

Despite the US's lack of regulation or restrictions over research that is not funded by the national government, several prominent bodies in the country have started to call for women to be "protected" in cloning research now that stem cell researchers in South Korea have devised an "efficient" way of creating new human embryonic stem cell lines. The "protection" focuses on the issue of payment (or rather on *not* paying the women), but several supporters of cloning research believe that such protection will decrease rather than increase the number of eggs available for research. For instance, the new California Institute for Regenerative Medicine, a publicly funded body, stipulates that women cannot receive payment for any eggs they give for research. It will reimburse expenses only, but does not define what qualifies for reimbursement nor set any limits on it.

In April 2005, meanwhile, the National Academies of Science issued guidelines governing the use of human embryonic stem cells. These included categorically *not* paying women for their eggs or even compensating them for their time and effort, but reimbursing only their direct expenses.<sup>31</sup> Incidentally, the guidelines seem not to have been motivated by concern for women's health or their potential exploitation, because they are "intended to enhance the integrity of privately funded human embryonic stem cell research by encouraging responsible practices".<sup>32</sup>

The UK, meanwhile, has been at the forefront, if not of cloning research itself, then at least of legalising, regulating and, to a certain extent, funding it with public money. The HFEA has issued two licences for human cloning research: the first in August 2004 to a team in Newcastle,<sup>33</sup> the other in February 2005 to a team at the Roslin Institute in Edinburgh led by Ian Wilmut, one of those involved in producing Dolly the cloned sheep, to research Motor Neurone Disease.<sup>34</sup> The Newcastle team has used eggs that did not fertilise in IVF procedures, whereas the Edinburgh research is using eggs donated by women before they are sterilised.

Since the South Korean developments, however, UK researchers have concluded that only "fresh" eggs will do, preferably those extracted from a woman just 30-60 minutes earlier, and preferably from women not known to have fertility problems.<sup>35</sup> Ian Wilmut now hopes to get "high quality eggs" by asking healthy women to donate them specifically for his research.<sup>36</sup> In contrast, "South Korea," says one commentator, "has a culture of egg donation for research, which enabled the scientists to obtain good-quality eggs".<sup>37</sup>

Is the international network of clinics that facilitates the trade in eggs for IVF well placed to expand into a trade in eggs for cloning research? Could it expand into countries where women of all colours who are not undergoing IVF themselves could be persuaded to provide their eggs? After all, if there's no baby, maybe racism plays less of a part and any woman's egg will do? South Africa is already an IVF "tourist"

destination, and an organ trade hub as well.<sup>38</sup> India's stem cell research, meanwhile, has been described as the “next big thing to hit India after the country’s software revolution,”<sup>39</sup> research that has been actively encouraged and supported financially by the Indian government. The main supply of stem cells in the country is from “left over” IVF embryos from the country’s more than 250 thriving IVF clinics, most of which are in the largely unregulated private sector.<sup>40</sup> Despite national guidelines to the contrary, “spare” human embryos are already travelling from IVF clinics in India to public and private research laboratories trying to isolate stem cells both in India and elsewhere.<sup>41</sup> The UK's eminent scientific institution, the Royal Society, is supporting various initiatives for scientists from the UK and India to exchange information and discuss possible collaborations and funding routes.<sup>42</sup> The Indian government’s long-term strategy is to encourage research into technologies that other countries find harder to do because their “ethical dilemmas”.<sup>43</sup>

I have my doubts, however, that the women targeted to supply the “resources” essential for cloning research will be that far from the cloning research's home because of the human egg's very biology. Cloning only seems to “work” with “fresh” eggs rather than those several hours old or frozen. Would the cloning labs move to the countries where women might provide eggs? Or would the eggs or the women themselves travel to the labs, somehow overcoming substantial restrictions on the free movement of people around the world? For the UK, maybe women within the poorer parts of free trade blocs such as the European Union would be targeted – Romania, after all, wants to become part of the European Union in 2007. For now, I suspect that women in the UK will be more in the spotlight for UK cloning researchers than those abroad.

What would persuade women in Britain to undergo the potentially hazardous egg retrieval procedure? UK bioethicist John Harris argued in March this year that people should be “morally obliged” to participate in scientific research, because he believes everyone in society stands to benefit from such research.<sup>44</sup> He contends that compulsion to participate in such research may, in certain circumstances, be justified, although financial incentives are preferable.<sup>45</sup> In the UK, could those receiving IVF treatment for free through the publicly funded National Health System be persuaded to feel they have a moral obligation to “give something back”?

### **Is Consent and Choice a Solution?**

Some argue that, as long as women give their free and full informed consent, it's up to them to take the risks of egg donation.<sup>46</sup> In recent years, various US and UK consultative commissions and policy-making bodies “have tended to assume that the way forward is to strengthen the rights of vulnerable individuals and populations by improving consent procedures”, an approach that at least recognises the imbalance of power between researchers and research subjects and thus seems to be “the key to eliminating injustice”.<sup>47</sup> In the United States, both the new California Institute for Regenerative Medicine and the National Academies guidelines suggest that women providing their eggs solely for research should sign consent forms indicating that they understand the risks of the egg retrieval procedure. The consent forms at the Romanian egg donation clinic – and indeed in the South Korean cloning research – did not mention that egg retrieval can be fatal.<sup>48</sup>

But is informed consent really possible given that the pharmaceutical industry has never carried out, nor been required by any government regulators to carry out, any studies into the short- and long-term health effects of taking the various hormonal drugs involved in egg retrieval? Without such information, can women really give their informed consent?

Even if some form of consent has been given, the doctors and medical staff involved are still bound first and foremost to “do no harm”.<sup>49</sup> Given the potential health hazards of egg extraction for which the woman would receive no benefit (such as the hope of a baby by means of IVF), clinicians could well be acting contrary to their duty and medical mandate. Moreover, the sheer numbers of human eggs required for cloning research could easily tempt researchers to overstimulate a woman’s ovaries so as to extract even more eggs than in an IVF procedure.

Moreover, several US and UK guidelines for egg donation, and for tissue donation in general, stipulate that the signatory understands they have no rights in any developments that arise out of the donation, such as a share of profits. The recent guidelines from the US National Academies, for instance, suggest that women should be told that although research involving their stem cells may have commercial potential, they will not share in any financial benefit.<sup>50</sup>

As legal and ethical feminist scholar Donna Dickenson points out:

“Whatever this is, it is certainly not an informed consent in the usual sense of a consent to the procedure itself; its purpose is not to protect the clinician from a possible battery action, but to preserve the commercial interests of researchers and their funders from later claims [from the person who donated the tissue].”<sup>51</sup>

Such a requirement gives the lie to the pretence of the gift relationship associated with egg donation, at least in the UK. Of UK Medical Research Council guidelines on tissue donation, Dickenson concludes that:

“Although the guidelines make a good deal of the ‘gift relationship’, what they are actually about is commodification. A compulsory and one-way gift relationship is not gift, but exploitation”<sup>52</sup>

In practice, therefore, “the semblance of gift masks and legitimises what is actually the extension of commodification”.<sup>53</sup>

“If donors believe they are demonstrating altruism, but biotechnology firms and researchers use the discourse of commodity and profit, we have not ‘incomplete commodification’ but complete commodification with a plausibly human face.”<sup>54</sup>

Ironically, when policymakers emphasise that women should “gift” their eggs having given their supposedly informed consent, women are perhaps exploited more than if the transaction was more transparent by means of payment. In any event, it is not “adequate to conceptualise the issue in terms of consent alone, any more than it is adequate to say that the worker consents to work and therefore retains no further rights to control the conditions of his labour.”<sup>55</sup>

A final problem of relying on informed consent alone stems from the practice's focus on the individual to the neglect of social, economic and political issues. What bearing does poverty or "no option at all" have on consent and choice? For Romanian women, "what relevance does the fact that 44.5% of Romania's population lives below the poverty line have?"<sup>56</sup> As US law professor Margaret Radin says:

"If we ban these exchanges without changing the circumstances that led to their seeming desirable to the would-be sellers, we seem to deny freedom of choice to those who are already harmed in their freedom of choice by racism and sexism."<sup>57</sup>

The remarks of US women's rights activist Marlene Gerber Fried about what can be problematic aspects of framing abortion rights in terms of "choice" also relate to women's "choice" to provide eggs for others:

"Because 'choice' appeals to those who have options, but is relatively meaningless to those who do not, it is politically divisive."<sup>58</sup>

Thus emphasis solely on the informed consent of patients, research subjects or donors, while seeming to empower the individuals involved, may in fact serve to bolster already powerful political and economic interests. The comments of philosopher Garrath Williams on biobanking are just as relevant to our concerns about women who provide eggs for research:

"To focus on individual rights may actually undermine individual rights and interest, in ways that benefit some organised interests, because important social, political and scientific questions are left out of consideration."<sup>59</sup>

### **Finding Other "Sources" of Human Eggs**

"Is commodification . . . worrisome not because of the mere fact of market pricing, but rather because of its linkage with sexism, poverty, or racism?"<sup>60</sup>

Even if moral obligations, financial incentives or informed consent were to become standard practice, however, it is doubtful whether enough women would supply enough of their eggs for research, let alone for clinical applications. Researchers are well aware of this limitation and are adapting their research accordingly. Those of us who are concerned about the commodification and commercialisation of women's bodies need to be aware of these alternative research avenues as well – they might be just as problematic for women in the long-term, particularly in terms of economic and social justice.

The South Korean team has certainly increased the "efficiency" of the cloning process. In 2004, they used 242 eggs from 16 women, of which 176 were suitable for cloning, to obtain 30 blastocysts from which just one stem cell line was developed; in 2005, however, they used 185 eggs from 18 women and are believed to have created more than 60 clones to get 11 stem cell lines: a 10-fold increase.<sup>61</sup> But as the *Financial Times* recently stated:



“even if therapeutic cloning can be made efficient, it is hard to see how enough human eggs could be made available to use the procedure in the clinic on a large scale (unless there is an unforeseen technical breakthrough)”.<sup>62</sup>

Take diabetes, for example, one of the diseases that the Newcastle cloning team are researching. There are an estimated 1.4 million diagnosed diabetics in the UK, and an estimated undiagnosed 1 million people. South Korean “efficiency” levels would suggest that two women would need to provide their eggs in order to derive one matched stem cell line for each diabetic – implying a total of 2.8 million women providing their eggs to treat UK diabetics. The estimated number of women aged between 20 and 34 years old resident in the UK as of mid-2004 is 5.8 million,<sup>63</sup> implying that one in every two to three women would need to go through the egg retrieval process just to treat diabetics.<sup>64</sup>

The figures are even more absurd for the United States, the world's premier pharmaceutical market on which all drug research has first and foremost to keep its eye. There are an estimated 17 million diabetics in the country, implying that 34 million of the 60 million US women of reproductive age would need to provide their eggs to help treat the disease.

Unsurprisingly, some researchers have been exploring other avenues to obtain – and even mass produce – human eggs:

-- **taking a slice from an adult woman’s ovary and researching how to get the cells to release a mature egg in the laboratory.** One advantage cited for this research is minimising a woman’s exposure to the health-threatening drugs used in egg retrieval.<sup>65</sup>

-- **taking ovaries from female foetuses aborted at a late stage and finding ways to mature their eggs in the laboratory.** After all, scientists believe that a female foetus has some 7 million eggs in its ovaries; whereas a new-born girl has just 1-2 million; a teenage girl even fewer, and just 400 on average are released in a woman’s lifetime.

-- **genetically engineering foetuses so that girls are born with their full 7 million complement of eggs.**

-- **creating eggs by getting human embryonic stem cells extracted from left over IVF embryos to develop into egg cells,** or simply fusing these embryonic stem cells with the cells from the sick adult patient so as to develop suitable transplant cells.<sup>66</sup>

When I learnt about these research avenues, I began to wonder whether my focus on the potential hazards for women in providing human eggs was perhaps too narrow – or perhaps just the tip of the iceberg. These other developments might not involve women's eggs and might not involve embryos, but they still have grave implications for health care, childcare, livelihoods, the public interest and gender equity and justice – issues that perhaps underlie our unease about egg donation in the first place. Maybe some prior questions need to be asked about why such research avenues are really being pursued, and who decided to follow and support them.

## Money, Money, Money

“Money matters, in science as elsewhere.”<sup>67</sup>

I now believe that, even if women were ultimately not required to donate or provide their eggs at all, critical issues of commodification and commercialisation would still remain. They remain because all the research is taking place within a commercial context that determines what gets researched and what doesn't, and which ensures that any resulting treatments would be commodities accessible only to those prepared to pay for them – commodities that may, in fact, have little to do with health. This is the case, *even if* public (that is, taxpayers' or citizens') money or charitable, non-profit foundation money funds the research – and even if women donate their eggs, organs and embryos for free until other research potentially renders such donations unnecessary. The commercial environment of both scientific research and of health care influences how and where research takes place, and affects who has access to any treatments that may result. Moreover, the wider current neo-liberal economic environment is a key determinant in why we become sick or infertile in the first place – and such sickness often has nothing to do with access to health care, commodified or otherwise. Analysis of who is paying for stem cell research illustrates some of these points and the changing notion of the “public interest”. After all, research – or knowledge production as it is increasingly described – is expensive and thus not undertaken lightly. And the more controversial the research, the more important is analysis of its funding.<sup>68</sup>

The history of funding research into molecular biology, genetics, reproduction and embryo research both in the last century and this is fascinating.<sup>69</sup> It ebbs and flows between wealthy individuals, universities, corporate foundations, governments, large corporations and venture capitalists in different countries and regions. An article in the *Financial Times* a few years ago on biotechnology regulation posed the question: who is regulating all the biotech activity? Its answer? “Firstly, the financial markets”.

But the financial markets, venture capitalists and pharmaceutical companies – all those who aim to make profit somehow out of their investments – have not been that interested in putting their money into embryonic stem cell research, even as they look forward to large markets for stem cell therapies in future.<sup>70</sup> “Venture capital, the traditional engine of biotechnology, is remarkably scarce in stem cells” comments *The Economist*.<sup>71</sup> Another *Financial Times* article in 2002 suggested that “the finances of the world's cloning companies are so precarious that a lack of funding may soon accomplish what moral objections have so far been unable to do: bring research in the area to a halt.”<sup>72</sup> This leading financial newspaper concluded three years later that the situation had barely improved: “There is little investment from traditional private sector sources such as venture capitalists and fund managers who see the field as too long-term and risky.”<sup>73</sup>

To prevent embryonic stem cell research from languishing, the public purse has been tapped. National and state governments in several countries are now committing “billions of dollars of public funds”<sup>74</sup> to keep embryonic stem cell research going. Of the \$1 billion spent on stem-cell research in 2004, more than four-fifths came from governments.<sup>75</sup> In the United States, although the national government will not fund research that involves the destruction of human embryos,<sup>76</sup> several individual states have proposed to spend several millions, if not billions, of dollars over the next

decade on embryo stem cell research. The citizens of California, the richest US state with an economy larger than that of the UK, voted for legislation in November 2004 to raise \$3 billion in public money over 10 years to support stem cell research and cloning techniques. The total cost to Californian taxpayers, however, will be about \$6 billion.<sup>77</sup> Other US states are now following suit.<sup>78</sup>

Public funding in any country invariably provides not just money but also acceptability, legitimacy and the prospect of additional private sector finance. Commenting on the new Californian legislation, for instance, the CEO of a San Francisco life sciences merchant bank, Burrill & Company, said:

“At present, stem cell science is tainted. Proposition 71 [the name of the Californian legislation] will legitimise a lot of research in the US, which under federal guidelines is perceived to be not investible”.<sup>79</sup>

In Britain, government funding for stem cells (including adult cells) is currently running at about US\$80 million a year. Money from the private sector amounts to just one quarter of this at US\$15-20 million.<sup>80</sup> Most of the public money for stem cell research goes to public universities. Last year, the UK set up, with public money, the world’s first stem cell bank.<sup>81 82</sup>

I used to think that public funding in democratic countries was committed “in the public interest” or for the “public good”. But just what is this public good or interest? Is it really “enabling people to live healthier, longer lives”, as many cloning supporters often claim, or are other “goods” involved?

I would argue that, in the process of state financial and legislative support being provided for genetic research, the public good or the public interest is being redefined as what is good for the economy, judged in abstract, statistical quarterly indicators. Behind the abstractions, however, are private, for-profit, interests: in essence, “the financial gain of a limited, circumscribed group”<sup>83</sup> – not necessarily what is good for citizens. Sociologists Henry Etzkowitz and Loet Leydesdorff are more explicit:

“The future legitimation for scientific research, which will keep funding at a high level, is that it is increasingly the source of new lines of economic development.”<sup>84</sup>

Three examples from the United States, the UK and Europe relating to biotech research in general illustrate this claim that public interests are becoming synonymous with the economic interests of a few. Legislation passed in 2003 in the US state of New Jersey allowing research cloning explicitly states that “the biomedical industry is a critical and growing component of New Jersey's economy and would be significantly diminished by limitations imposed on stem cell research”.<sup>85</sup>

Meanwhile, the goal of UK publicly funded strategic scientific research over the past ten years has been “to produce a better match” between such research and “the needs of industry”. The mandate of the UK government body dispersing biotech funds, the (Biotechnology and Biology Social Research Council (BBSRC) is “to sustain a broad base of interdisciplinary research and training to help industry, commerce and Government create wealth”<sup>86</sup> – the last word does start with a “w”, not an “h”. Representatives from pharmaceutical, chemical and life science companies are on the boards making the funding allocation decisions.

For the European Union, its goal in research funding, known as the Lisbon Strategy, is to make Europe “the most competitive knowledge-based economy in the world”<sup>87</sup> by the year 2010.<sup>88</sup> The European Commission has said that:

“selecting genomics and biotechnology for health as one of the priority themes [for research funding] . . . is in line with a major political and strategic choice the Union made recently in meeting the challenges of the new knowledge-based economy.”<sup>89</sup>

As the European Science Social Forum Network (an alliance of civil society organisations) has pointed out, “such an approach supports and judges research and innovation only in its ability to deliver money-making ventures, not whether it can make society a more sustainable and healthy place to live”<sup>90</sup>

### **The Effects of Public Policy**

Does it matter if the public purse subsidises the private sector in this way? Does it matter if some people make profit out of genetic or embryonic stem cell research, or out of any resulting products, as long as sick people get better therapies or drugs in the end that they wouldn’t get otherwise? Does it matter, in sum, if the public interest is redefined as the private interest of a few?

If the goal is economic and social justice, the short answer is “Yes”, but the reasons for the answer are long. For now, I’ll be brief.

Simply pouring public money into embryonic stem cell research (and genetic research more generally) is no guarantee that the general public will have access to any of the “goods” that result, either in terms of profits or products. Patents – monopoly privileges in effect – are a major cause of such restricted access. Even if public or charitable money has paid for research, any resulting “inventions” are invariably patented, thereby curtailing access to the knowledge or products unless researchers and sick people alike can pay for them. Some US health researchers have concluded that:

“When public funds have supported any aspect of research, it is difficult to reconcile the issuing of patents and the sealing off of proprietary information with the public interest.”<sup>91</sup>

It is not difficult to reconcile, however, if “the public interest” is understood as private gain within a neo-liberal “free trade” economic framework and if public policy has shifted from aiming at social protection to encouraging capital accumulation. As Canadian law scholar Roxanne Mykitiuk has pointed out:

“The state no longer sees itself as defending the public interest against the private interest of private actors, but sees itself as promoting the interests of private actors as the potential benefactors of the public through the production of health commodities . . . In moving away from defining and representing the public interest, and towards a model of product liability and intellectual property, the state is shifting the arena of adjudication into the area of commercial law and away from public and constitutional law.”<sup>92</sup>

Despite ethical qualms about embryo research and despite a lack of private funding, it seems that patents on stem cell research, both embryonic and adult (including foetal) cells, are proliferating. According to a recent report by a British legal firm of patent lawyers:

“Worldwide, over 3,000 applications have been published in the field of stem cell technology [including adult stem cells] since 2000, more than 50% of which have been filed in the US . . . [B]y far the majority of patents have been granted in the US (more than 1,300, compared with 64 in Europe).”<sup>93</sup>

“Of the total number of patent families filed worldwide in this period [2000-2004 inclusive], around one quarter relate to embryonic stem cell technology. The split between embryonic and other stem cell technology varies by country, from 15% embryonic stem cell related filings in the US, to nearly 40% in the UK, reflecting the more liberal research regime in the UK.”<sup>94</sup>

Much of this patenting has been carried out by publicly funded universities. As the government has retreated in recent years from funding basic academic research, many universities have had to start looking for other sources of funding, including from the for-profit sector. They have taken out patents on their own research so as to fund their continued existence, and have taken money from pharmaceutical companies to carry out industry research. What has gradually happened in the US is now happening in the UK: most research becomes tied-up with commercial interests. Increasingly, there are fewer and fewer independent scientists to call upon to assess whether a product is safe and in the public’s genuine interest.<sup>95</sup>

Another related reason why sick people are unlikely to have access to any treatments or drugs that may result from embryonic stem cell research is because health care services themselves are being commercialised and commodified. Any products will go to those who can afford to pay for them, assuming the market is big enough to be profitable. In many countries, the public sector has retreated from providing free, quality health care services, while any public money that is allocated to health care is increasingly channelled to for-profit services. Such an approach to health care not only drives up the costs, but also less attention being paid to the factors that make people ill in the first place, many of which may have nothing to do with health care services at all. Such an approach promises (falsely) that medical technology can fix diseased individuals and that good health can be bought and sold in the marketplace rather than being something to promote or work for in other ways.<sup>96</sup>

Given prevalent neo-liberal economic trends around the world, it is perhaps not surprising that personalised genetically matched transplants (and other genetic products) are being promoted. Both genetic and neo-liberal economic models emphasise the individual and downplay the importance of wider society or environment. As Roxanne Mykitiuk says, “the new genetics contribute to a re-defined ‘neo-liberal’ self, which is responsible for the private management of real and potential risks to health.” It also as an appeal to the neo-liberal state “as a means to develop the industrial potential of the knowledge-based economy, particularly in the health care market.”<sup>97</sup>

The patenting of embryonic stem cell research (and genetic research more widely) thus provides only a partial explanation as to why such research may not ultimately be of any “benefit” to sick people. Even if the research was made openly and freely

available, following the examples of the open source software movement, the products might be cheaper but still not accessible if there are no health services to provide them.

Thousands of people die prematurely each year in Britain, the fourth wealthiest country in the world, because of three factors: unemployment, child poverty, and inequality of income and wealth. All are directly related to government policies, legislation, and the allocation and use of public money. But at present in the UK, public money, policy and legislation is increasingly directed towards private, for-profit interests and thus away from other avenues of health and scientific research, away from other means of job creation, and away from other ways of organising and conducting the country's economy.

## **Conclusion**

The aim of this workshop is to explore perspectives for feminist intervention given the rapid and increasing commodification and commercialisation of women's bodies in reproductive (and other) technologies. I'm conscious that I've introduced many aspects related to this trend: women's eggs, medical research, consent, economics, public interest, health care systems, poverty – far too many to lead to a simple discrete intervention. But like women themselves, many of these aspects have been excluded from debates and decisions about new technologies. Unless they are brought in, I fear that any intervention we may make may have limited positive effect, or even a retrogressive effect, not only in the longer term if the ultimate goal is gender justice, but also, and just as importantly, in the immediate term if the goal is simply to widen awareness of the potential harms to women of egg donation.

## **Post-Script February 2006**

Soon after the South Korean team's announcement in 2004 that it had created cloned human embryos from which it had extracted stem cells, controversy grew as to how these eggs had been obtained. Reports began to circulate that the donors may have been women postgraduate students of the lead researcher, Professor Hwang Woo Suk.<sup>98</sup>

In October 2005, Professor Hwang announced the establishment of a World Stem Cell Hub Foundation, a consortium based in South Korea but with satellite laboratories in the UK and the US. The three laboratories aimed to create embryonic stem cell lines using eggs from women recruited locally under the supervision of Professor's team. The idea was that scientists from around the world, particularly in countries that do not allow embryos to be created and/or destroyed, could ask these laboratories to "make" whatever cell line they needed for their specific disease research. The consortium was likened to an offshore company set up to avoid tax laws; in this case, it would enable researchers to sidestep domestic restrictions on such research.<sup>99</sup>

Just one month later, however, in November 2005, the whole project was floundering after the US researchers pulled out, accusing Hwang of obtaining eggs from his junior researchers (unethical because of the potential for them to feel coerced) and of misleading a US collaborator about the source of the eggs.

Hwang initially denied the accusations and defended his research, but later admitted that he had lied about using his researchers' eggs and resigned all his official positions. The head of a Seoul hospital said he had paid about \$1,443 to women who had provided their eggs for Hwang's research.<sup>100</sup>

Then, in December 2005, one of Hwang's colleagues claimed that the evidence for cloning human embryos and extracting stem cells had been faked. Hwang's employer, Seoul National University, set up an investigation, which concluded in January 2006 that Hwang and his colleagues had completely falsified the evidence for his papers in *Science*.

The University's investigation concluded that claims in the first *Science* article in 2004 that an embryonic stem cell line had been derived from a cloned blastocyst were false because the cell line did not match the DNA of the woman from whose egg the line was supposed to have been derived.

The University also reported that the data in the second *Science* paper in 2005 had all been fabricated. The article claimed that 11 human embryonic stem cell lines had been established, when in fact the data referred to only two embryonic stem cell lines – and these two lines had been derived from fertilised eggs, not from cloned embryos. "In conclusion", said the University's report, "the research team of Professor Hwang does not possess patient-specific stem cell lines or any scientific bases for claiming having created one." In sum, "the scientific bases for claiming any success are wholly lacking." *Science* has since retracted both papers.

The University also examined the propriety of the procedure for acquiring and using human eggs. Far from being unaware of laboratory members donating their eggs, Professor Hwang had accompanied one of them to the hospital himself for the procedure. In May 2003, his research team had circulated a consent form for voluntary egg donation, which several women technicians had signed.

The University reported that from November 2002 to November 2005, a total of 2,061 eggs from 129 women were collected from four hospitals and provided to Professor Hwang's team – nearly five times the number described in the two *Science* papers. This would suggest even more intensive ovarian stimulation than the published figures had indicated. In February 2006, a coalition of 35 women's groups filed a suit for compensation against the South Korean government on behalf some 20 per cent of the women who provided eggs on the grounds that they had not been informed of the "side-effects" of donation. The effects were so severe in some cases that a number of the women were hospitalised. Fifteen women donated eggs more than twice<sup>101</sup>

There has been international condemnation of the fraud involved in this research, but little outrage or attention paid to the team's "breaches of ethical guidelines designed to protect women from exploitation and medical harm". The editor-in-chief of *Science*, Donald Kennedy, said that he "would not have been bothered" by allegations that the eggs were provided by junior researchers. *New Scientist* comments, "Hwang betrayed the trust placed in him by his peers. But his cavalier disregard for the women he exploited, and for the patients whose hopes have been dashed, was far worse."<sup>102</sup>

*The Korea Times* has reported that, based on the University's report, the South Korean authorities are considering a criminal investigation into Hwang's obtaining taxpayers' money fraudulently and misusing it. From 1998 to 2005, the government

provided more than 62.3 billion *won* (\$63 million) to Hwang's team, including research funds and financing the construction of laboratories.<sup>103</sup>

After these "Hwanggate" revelations, other research teams may well step up their efforts to extract stem cells from cloned embryos, given that it would seem the South Korean team has not managed to do so after all. The UK government has announced that it would double its spending on stem cell research to about \$180 million over the next two years.

But the controversy could also deter further research. If Hwang's team did not in fact extract patient-specific stem cells from cloned human embryos, scientists have few clues as to how it might be accomplished – and doing so is clearly even more difficult than anticipated.

Chris Shaw, a neurologist at King's College London, who with Ian Wilmut, heads one of the two groups in the UK researching human embryo cloning, believes that research into patient-specific stem cells has been set back significantly by the Hwang controversy.

“The problem is that Dr Hwang had a better chance to crack this than anyone else, because of his extraordinary access to fresh human eggs in their thousands, which is going to be very difficult to reproduce anywhere else in the world.”<sup>104</sup>

Recognising that women may now be even more reluctant to provide their eggs for cloning research, Shaw and Wilmut are now seeking permission to use rabbit eggs to create human stem cells so as to study motor neurone disease. The head of research regulation at the HFEA, has said that mixing human and animal material is “complex and not thoroughly and explicitly dealt with under the current legislation”.<sup>105</sup>

Wilmut has also proposed that experimental stem cell “treatments” should be tested on terminally ill patients before such treatments have been proven safe in animal experiments so as to speed up the pace of research.<sup>106</sup>

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<sup>1</sup> Margaret Jane Radin, *Contested Commodities: The Trouble with Trade in Sex, Children, Body Parts and Other Things*, Harvard University Press, Cambridge, MA 1996, p.154.

<sup>2</sup> Those most commonly mentioned are: spinal cord injuries causing paralysis; insulin-dependent diabetes; Parkinson's disease; Lou Gehrig's disease (amyotrophic lateral sclerosis), also called motor neurone disease; muscular dystrophy; multiple sclerosis; heart failure; kidney failure; blindness and baldness.

<sup>3</sup> The UK expressly legalised embryo research (and IVF) in 1990 and established the Human Fertilisation and Embryology Authority (HFEA) in August 1991 to license and monitor all human embryo research being conducted in the UK, the first statutory body of its type in the world. Most embryo research until recently has been connected with reproduction in some form, either to facilitate it or prevent it. In 2001, UK legislation was amended to permit research on embryos for serious diseases. The UK is one of the few countries in the world that allows embryos to be created legally in the laboratory expressly for research, not to result in a baby. (That said, the numbers of embryos created for research are in their hundreds compared with the thousands left over from IVF procedures.) The HFEA also regulates and inspects all UK clinics providing IVF, donor insemination or the storage of eggs, sperm or embryos. (<http://www.hfea.gov.uk>)



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In 2004, the UK government decided to review the 1990 Human Fertilisation and Embryology Act, “given the rise of new technologies, changes in societal attitudes, international developments, and the need to ensure effective regulation.” It is running a public consultation on changes to the legislation from August to November 2005, but has already proposed to replace the HFEA and another government body, the Human Tissue Authority, with a single body, the Regulatory Authority for Tissue and Embryos (RATE), by April 2008, which would have responsibilities across a range of human tissues and cells. *See* Department of Health, *Review of the Human Fertilisation and Embryology Act: A Public Consultation*, August 2005, <http://www.dh.gov.uk/publications>

<sup>4</sup> Developmental biologist Dr James A. Thomson, and colleagues at the University of Wisconsin first established five independent embryonic stem cell lines in the laboratory from the inner cell mass of blastocysts (embryos of about 140 cells) once the outer cellular layer has been dissolved. (James A. Thomson et al, “Embryonic Stem Cell Lines Derived from Human Blastocysts”, *Science*, 6 November 1998, Vol. 282, pp.1145-1147)

The work was paid for by the Californian biotechnology company, Geron Corporation. In 1999, Geron acquired Roslin Bio-Med, the company set up by the Roslin Institute that produced Dolly the cloned sheep. Geron agreed to provide £12.5 million in research funding to the Roslin Institute over the following six years. Geron thus acquired the patent to the Dolly cloning technology that had been part funded with UK public money.

Nonetheless, “after seven years of intensive work worldwide, the world has fewer than 150 well-characterised ES [embryonic stem] cell lines, because the process of establishing them is extremely tricky.” (Clive Cookson, “Mother of All Cells” in *The Future of Stem Cells*, *Financial Times & Scientific American* Special Report, July 2005, p.A6.)

<sup>5</sup> Resource, shortage, waste and surplus are all economic concepts. Given the commercial framework within which IVF and embryo research takes place, such terms are perhaps appropriate and an indication of the commodification and commercialisation of women’s bodies that has already taken place. I put the words in quote marks, however, to highlight this problematic economic aspect and to encourage debates on these topics as well as the more familiar ones on the morals or ethics of embryo research. For a critique of the term “resource”, *see* Larry Lohmann, “What Next? Activism, Expertise, Commons”, The Corner House, September 2005, <http://www.thecornerhouse.org.uk/subject/dams>

<sup>6</sup> Overall, growing stem cells in the laboratory has proved far more problematic than many than researchers expected. These cells accumulate more and more genetic changes, including mutations linked to cancer. Moreover, most existing human embryonic stem cell lines have been contaminated with animal cells used as a growth medium in the lab dishes; these cells would trigger damaging immune responses if transplanted into a person. Such findings, however, have only added to pressure for new embryonic stem cell lines to be created (Roxanne Khamsi, “Gene defects plague stem-cell lines”, *Nature*, UK, 5 September 2005, <http://cmbi.bjmu.edu.cn/news/0509/22.htm>).

<sup>7</sup> This technology is variously called somatic cell nuclear transfer (SCNT), embryo cloning, research cloning, therapeutic cloning, and reproductive cloning, depending on what is envisaged for the embryo created. Other avenues being explored to immune rejection are:

- freezing at birth umbilical cord cells because these contain stem cells;
- genetically engineering embryonic stem cells taken from an unrelated embryo.

<sup>8</sup> I tend to use the word “egg” as an attempt to communicate as widely as possible rather than the strictly biological terms ovum, ova or oocyte (egg cell).

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<sup>9</sup> Woo Suk Hwang et al, "Evidence of a Pluripotent Human Embryonic Stem Cell Line Derived from a Cloned Blastocyst", *Science*, 12 March 2004, Vol. 303, pp.1669-1674 (since retracted, see Post-Script at end of this document).

<sup>10</sup> Woo Suk Hwang et al, "Patient-specific embryonic stem cells derived from human SCNT blastocysts", *Science*, 17 June 2005, Vol. 306, pp.1777-1783 (since retracted, see Post-Script at end of this document).

<sup>11</sup> Dr James A. Thomson, who led the team that first isolated embryonic stem cells in the laboratory in 1998, said in June 2005 that he thought current prospects for transplantation cures from stem cell lines are unrealistic, that existing stem-cell lines are not suited to such applications, and that he does not believe there is a need to resort to therapeutic cloning. (Alan Boyle, "Stem cell pioneer does a reality check: James Thomson reflects on science and morality", 25 June 2005, <http://www.msnbc.msn.com/id/8303756/>. accessed 1 September 2005)

Dr Alan Trounson in Australia, a world expert on embryonic stem cells, was reported in *Nature Medicine* in May 2005 as saying that "the so-called therapeutic cloning to my mind is a non-event". As a way of creating cures, "it's just not realistic". Dr Jose Cibelli of Michigan State University, who has worked with the US cloning company, ACT, said, "I can predict that therapeutic cloning is going to be obsolete" (Michael Cook, "Promises of miracles a false one", *The Australian*, 23 May 2005).

In the UK, fertility research pioneer Robert Winston, who pushed for UK legislation in 2001 to allow embryo research to treat diseases, now warns of a public backlash when it becomes clear that cures are not just around the corner. "We may have oversold this subject a bit too much", he concedes (Tim Radford, "Stem cell hopes distorted by 'arrogance and spin'", *The Guardian*, 5 September 2005).

What these researchers do believe, however, is that it should be possible to direct embryonic stem cells to develop into the various different cell types of the body and then use them to test quickly thousands of chemicals for their effectiveness in treating diseases, circumventing the need for some human and animal clinical trials. "Nobody's been able to test heart drugs on heart cells [outside the human body] before," said Dr James Thomson. "That will change medicine a lot quicker than actually transplanting those heart cells." Thomson has predicted that, in the long run, embryonic stem cells will play a more important role in fundamental research than in transplantation therapies.

<sup>12</sup> This phrase is more frequently used to describe the consequences of sex selection in India and China when girl babies are aborted or abandoned. It would perhaps not seem to be an appropriate phrase to describe women's involvement in IVF and cloning research, because they are essential to the procedures. Nonetheless, I believe there are similarities between the practices and consequences of sex selection and embryo research that merit further explorations, and thus use the phrase "missing women" to encourage such exploration.

<sup>13</sup> "Donates" suggests that eggs, blood, organs and tissue are given voluntarily to others for free out of altruism. Many people do so with this motivation, but because "donations" are increasingly taking place within a commercial context, I'm not sure whether "donate" is an accurate verb to use. "Provides" may be a more suitable verb as it hints at the commercial background, even though it should not be taken as an endorsement of such a background. "Sell" is clearly appropriate in some instances.

<sup>14</sup> The first IVF baby born from a donated egg was born in 1983. In 2002-3, 1 in 20 licensed treatments (4.9%) in the UK involved the use of donor eggs compared to almost 1 in 35 treatments (2.9%) in 1994-95. Between 2004-2005, 51.2% of registered egg donors were aged

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31-35, while 29.4% are aged 25-30. Just 10% were aged 18-24 years. (HFEA, *SEED Report*, HFEA, London, October 2005)

<sup>15</sup> Dr Paul Rainsbury, who runs a fertility clinic in London, claims that "there is now a waiting list for two to eight years in this country for egg donations". Since April 2005, anyone donating sperm, eggs or embryos can no longer remain anonymous. Children born as a result of sperm, eggs or embryos donated after April 2005 will be able to access the identity of their donor when they reach the age of 18. The loss of anonymity has exacerbated the egg shortage. "Ten years ago when we put out an advert asking for egg donors we would get 20 replies," said Rainsbury. "Now we get none". ("Fertility Tourism", 22 September 2004, <http://www.ifeminists.net/introduction/editorials>. accessed 14 June 2005)

<sup>16</sup> Helena Echlin, "How much would you pay for this?", *The Guardian* (G2) 25 July 2005, pp.10-11.

<sup>17</sup> To obtain human eggs for the laboratory, women typically undergo hormonal treatment to "shut down" and then stimulate their ovaries to produce multiple eggs rather than the usual one, followed by surgical extraction of anything from a few eggs to 20 or more.

A former Chief Medical Officer of the US Food and Drug Administration, Suzanne Parisian, stated in February 2005, "Although it is common practice in IVF facilities to extract eggs as part of infertility treatment, many of the drugs used during these procedures have not been adequately studied for long term safety, nor do some of these drugs have FDA approval for these specific indications. This is not widely understood and has led to significant misunderstanding about the risks involved for women who donate eggs, whether for reproductive purposes or for SCNT [somatic cell nuclear transfer] research." (Open Letter from Suzanne Parisian, February 2005. <http://www.genetics-and-society.org/resources/items>, accessed 8 April 2005)

The drug most commonly used to shut down a woman's ovaries initially, leuprolide acetate or Lupron™, has reportedly caused severe joint pain, difficulty in breathing, chest pain, nausea, depression, dimness of vision, loss of pituitary function, hypertension, rapid beating of the heart, asthma, generalised edema and abnormal liver function.

The drugs used to stimulating the ovaries to produce multiple eggs can cause the potentially fatal Ovarian Hyperstimulation Syndrome (OHSS), which can involve the development of many cysts, enlargement of the ovaries and massive fluid build-up in the body, particularly in the abdomen, lungs and other tissues. OHSS is also associated with increased risk of clotting disorders, kidney damage and ovarian twisting. Other risks associated with egg extraction include respiratory or cardiac arrest, brain damage, paraplegia, paralysis, loss of function of a limb or organ, haemorrhage, allergic reaction, and infection. (Judy Norsigian, "Egg Donation for IVF and Stem Cell Research: Time to Weigh the Risks to Women's Health", *Different Takes*, No. 33, Spring 2005, <http://popdev.hampshire.edu/projects/dt/dt33.php>; <http://www.genetics-and-society.org/resources/background/eggextraction.html>)

<sup>18</sup> Because eggs do not freeze well, they cannot simply be extracted and sold to the highest bidder at a later stage. Arrangements need to be in place before the eggs are extracted as to whose sperm will fertilise the egg and into whose uterus the resulting embryo will be inserted.

<sup>19</sup> Richard Titmuss, *The Gift Relationship: From Human Blood to Social Policy*, Allen and Unwin, London, 1971.

<sup>20</sup> This is still the official public line, even though body organs are definitely "Wanted" whether the person is "dead or alive" because of a "shortage". Fewer organs are available in

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the UK for transplant because road safety has improved in recent years, reducing the number of fatal traffic accidents.

Altruistic donation is also encouraged for the UK's biobanks (Garrath Williams, "Bioethics and large-scale biobanking: individualistic ethics and collective projects", *Genomics, Science and Policy*, Vol. 1, No. 2, 2005, pp.50-66, p. 51. <http://www.lancs.ac.uk/fss/journals/gsp>)

<sup>21</sup> But are the payments gender equitable or just? In practice, sperm donors are paid approximately £300-400 for donating over an average of 19 sessions, whereas egg donors tend to donate just once and therefore receive just £15 even though they spend approximately the same cumulative amount of time at the clinic as sperm donors. In addition, whereas men can simply masturbate to produce sperm, women take hazardous hormonal injections over several weeks and then undergo surgery for the eggs to be extracted. The disparity in payment in practice is bolstered by the idea that women donate out of altruism but men need some form of exchange.

<sup>22</sup> This combination of "no payment but reasonable compensation" is continued in the EU's Tissue Directive. Directive 2004/23/EC on setting standards of quality and safety for the donation, procurement, testing, processing, preservation, storage and distribution of human tissues and cells which was adopted on 31 March 2004. The Directive states that:

"As a matter of principle, tissue and cell application programs should be founded on the philosophy of voluntary and unpaid donation, anonymity of both donor and recipient, altruism of the donor and solidarity between donor and recipient. Member States are urged to take steps to encourage a strong public and non-profit sector involvement in the provision of tissue and cell application services and the related research and development." [Preamble (18)]

Article 12, paragraph 1, states that:

"Member States shall endeavour to ensure voluntary and unpaid donations of tissues and cells. Donors may receive compensation, which is strictly limited to making good the expenses and inconveniences related to the donation."

The Directive also states that "It is necessary to promote information and awareness campaigns at national and European level on the donation of tissues, cells and organs based on the theme 'we are all potential donors'." [Preamble, paragraph (3)]

<sup>23</sup> In fact, the HFEA set a limit of £250. Its *SEED Report*, published on 7 October 2005, concluded that:

--donors may be reimbursed all demonstrable out-of-pocket expenses incurred within the UK in connection with gamete or embryo donation. (The HFEA set no upper limit to these expenses, but restricted them to those incurred within the UK to prevent men and women coming to the UK on a fully-funded trip so as to donate.)

--in addition, donors may be compensated for loss of earnings (but not for other costs or inconveniences) up to a daily maximum commensurate with jury service (£55.19 per day) but with an overall limit of £250 (or the equivalent in local currency) for each 'course' of sperm donation or each cycle of egg donation.

--gamete donors may receive benefits in kind in return for supplying gametes for the treatment of others but these benefits should be limited to discounted treatment services.

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--procurement of gametes from abroad should fulfil the same quality standards as apply in the UK and the HFEA would expect to authorise imports only where these standards can be met. (<http://www.hfea.gov.uk/AboutHFEA/HFEAPolicy/SEEDReview>)

<sup>24</sup> The popular or media term to describe this practice is “IVF tourism”. But as British social scientist Naomi Pfeffer points out, the term stigmatises infertile women, very few of whom are privileged. Infertility is associated with poverty, and the main known causal factors are being overweight, smoking and pelvic inflammatory diseases. The real IVF tourists, Pfeffer points out, are private clinic owners and biotech companies.

<sup>25</sup> quoted in David Derbyshire, “Law on anonymity drives would-be parents abroad”, *The Daily Telegraph*, 14 June 2005 (article filed 3 July 2004). <http://www.telegraph.co.uk/news>, accessed 14 June 2005.

<sup>26</sup> The HFEA does not regulate IVF outside the UK, but has authority over any in-vitro eggs, sperm or embryos coming into the country. In 2004, the HFEA had given permission (“Special Directions”) to the private Bridge clinic in London to import gametes from Romania, in particular, embryos created from donor eggs from Romanian women and the sperm of a man in the UK. But in June 2004, it “placed an embargo on the import of gametes from Romania” because it had concerns “about the literature that donors were being provided with”. In particular, the literature “did not explain the procedure of extracting eggs from the donors properly and the change in donor anonymity laws in the UK” (see footnote 15 above). “A small team from the HFEA visited the clinic in Romania and found that whilst procedures seems [sic] to be of a good standard, they asked that the Bridge clinic oversee changes to the donor information . . . The current situation [4 February 2005] with Bridge/GlobalART is that there have been development in terms of changing the literature but a decision to lift the embargo has not been lifted yet.” (Email from Lara Gorma, press officer, HFEA to Erika Feyrabend, 4 February 2005.)

<sup>27</sup> <http://www.globalartusa.com/>

<sup>28</sup> Women of colour in the US have historically been presented with reproductive technologies designed to limit rather than facilitate births, particularly sterilisation and long-acting contraception (Roberts, D., *Killing the Black Body: Race, Reproduction and the Meaning of Liberty*, Vintage Books, New York, 1997).

<sup>29</sup> According to Robert Lanza, a scientist with ACT, the US company that made early but unsuccessful attempts at making cloned human embryos. Quoted in Rick Weiss, “S. Korean Scientists Describe Cloning: Others Worry Over Who Will Use Data”, *Washington Post*, 13 February 2004, p. A13.

<sup>30</sup> The Bedford Foundation advertises for donors in Boston newspapers and pays each woman about \$4,000, although the Foundation’s costs in total for each donor are about \$25,000 to cover counselling, medical check-ups, childcare and travelling expenses. The Foundation has suspended the program four times since 2001 because it ran out of money. Because of the time involved in providing eggs, working women are unlikely to donate, meaning that the wealthy or the jobless will be the likely candidates. (Paul Elias, “Cloning Sparks Concern Over Egg Donors”, Associated Press, 10 March 2005. See also <http://www.bedfordresearch/aboutus/aboutus.php>, accessed 30 August 2005)

<sup>31</sup> “Women who undergo hormonal induction to generate oocytes specifically for research purposes (such as for nuclear transfer) should be reimbursed only for direct expenses incurred as a result of the procedures . . . No cash or in kind payments should be provided for donating oocytes for research purposes. . . . This recommendation is based, in part, on the recognition that payments to oocyte donors raise concerns that might undermine public confidence in the

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responsible management of hES cell research.” (Guidelines for Human Embryonic Stem Cell Research, National Academies Press, 2005, p.87.

<http://www.nap.edu/books/0309096537/html/81.html>, accessed 30 August 2005)

<sup>32</sup> “Guidelines Released for Embryonic Stem Cell Research”, press release, 26 April 2005, The National Academies, <http://www4.nationalacademies.org/news.nsf.isbn/>, accessed 30 August 2005.

<sup>33</sup> This team at the Newcastle Centre for Life within the University of Newcastle upon Tyne announced in May 2005 that it had cloned a human embryo, but it survived for five days only and the scientists were unable to extract embryonic stem cells.<sup>33</sup> The single clone was derived from 36 eggs from 11 women undergoing IVF. (Ian Sample and Donald MacLeod, "Cloning plan poses new ethical dilemma: Scientist courts controversy with call for women to donate eggs", 26 July 2005, *The Guardian*.)

<sup>34</sup> The Scottish team plan to create cloned embryos in order to discover why the nerve cells of those with Motor Neurone Disease die off and perhaps to test new drugs, but not to “correct” the disease directly. When the existence of Dolly the cloned sheep was announced to the world in February 1997, Ian Wilmut stated that the technologies must never be applied to humans.

<sup>35</sup> New research, however, suggests that even embryos created from eggs from young, healthy women contain more genetic abnormalities than previously thought. (Ian Sample, “IVF embryos have genetic defects”, *The Guardian*, 4 November 2005)

<sup>36</sup> Ian Sample and Donald MacLeod, “Cloning plan poses new ethical dilemma: Scientist courts controversy with call for women to donate eggs”, *The Guardian*, 26 July 2005.

Ian Wilmut has expressed interest in working with the South Korean team; Professor Hwang’s response was that he needed to consider the country’s “national interest” and to “talk with the government” before doing so. Others in the UK intend to take some of their stem cell research to India. (Richard Gardner and Tim Watson, “A Patchwork of Laws” in *The Future of Stem Cells, Financial Times & Scientific American Special Report*, July 2005, p.A19; Kim Tae-gyu, “Dolly Creator Wants to Work With Hwang”, *The Korea Times*, 6 April 2005)

<sup>37</sup> Clive Cookson, “The Cloning Connections” in *The Future of Stem Cells, Financial Times & Scientific American Special Report*, July 2005, p.A11 (see Post-Script at end of this document).

<sup>38</sup> South African law forbids the sale of organs for transplantation and requires the establishment of some relationship between donor and recipient. Several doctors and medical staff are currently facing trial in the country for transplanting kidneys, sold by Brazilians for up to \$10,000 each, into Israelis who paid up to 10 times that amount, all the operations taking place in South Africa. The main financial beneficiaries, however, seem to be the intermediaries. (Pat Sidley, “South African doctors charged with involvement in organ trade”, *British Medical Journal*, Vol. 329, 24 July 2004, p.190.)

<sup>39</sup> C. Thorold, “Indian Firm Embrace Biotechnology”, *BBC News*, 6 April 2001, quoted in Aditya Bharadwaj, “Cultures of Embryonic Stem Cell Research in India” in Wolfgang Bender, Christine Hauskeller, Alexandra Manzei (eds.) *Crossing Borders: Cultural, Religious and Political Differences Concerning Stem Cell Research*, Agenda Verlag, Münster, 2005.

<sup>40</sup> There is little information on infertility among women in India, not least because studies and policies usually focus on “overpopulation” and limiting fertility. But estimates suggest that some 3-8% of women become pregnant and cannot give birth. As elsewhere in the world,

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infertility seems to be associated with sexually transmitted diseases, poor health and nutrition, previous contraceptive use, and lack of access to quality health services and clean water. Infertility is almost always deemed to be the woman's problem and can be disastrous in societies in which "fertility defines womanhood and womanhood is defined by a woman's capacity to 'mother'".

Anjali Widge attributes "the extreme importance given to fertility in Indian society" to "the system of patriarchal descent, patrilocal residence . . . property inheritance, lineage and caste". Because of these social pressures, women will go through all kinds of treatments to have a biological child, preferably a son. Having children "brings them power in real terms, and . . . for many it is the only power-base they have from which they negotiate the terms of their existence." Given this background, private, for-profit IVF clinics have flourished without regulation or legislation, while preventive or curative services for infertility have not been a priority for the public or private sector. Concludes Widge, "in the present context of consumerism and market-oriented technologies, the private health care sector and the pharmaceutical and genetic engineering companies use the slogan of 'help for the infertile', but it is the companies that stand to gain." Widge's comments about critiques of IVF are also relevant to our concerns about women providing eggs for cloning research:

"Experiences of infertile women with reproductive medicine are not very pleasant but they still want to use the technology, sometimes because it helps them negotiate their position in the patriarchal family. Also, an overemphasis on the negative impact of these technologies distracts attention from the politics and organization of health care in general, from the legal system, from political struggles over the nature of sexuality, parenthood and the family, and from the impact of the varied material and cultural circumstances in which people create their material lives."

(Anjali Widge, "Sociocultural attitudes towards infertility and assisted reproduction in India", in Effy Vayena, Patrick J. Rowe and P. David Griffin (eds.) *Current Practices and Controversies in Assisted Reproduction*, WHO, Geneva, 2002, pp.60-74, <http://www.who.int/reproductive-health/infertility/11.pdf>)

<sup>41</sup> Sociologist Aditya Bharadwaj asks "What can possibly explain India's tryst with the 'scientific high culture' of biotechnology given that primary curative health care needs of millions are as yet unmet?" Indian stem cell research is "even more intriguing given that there are no immediate therapeutic benefits or so-called imminent downstream applications on the horizon". One answer is that the "new generation of market-led research in genomics, proteonomics, transgenics and stem cells" has emerged because of "nationalistic imaginings of techno-scientific advancements". Such wishes have led the Indian government to invest significantly in biotechnology over the past 20 years. Another answer is that India would rather do stem cell research itself than become an "embryo surplus nation" for "foreign scientists". Bharadwaj points out, however, that:

"emerging anecdotal evidence from India . . . suggests that there is an existing steady supply of human gametes to Western Europe. . . . This commodification and Indianisation of semen, eggs, embryos and stem cells goes much deeper than the media outpourings on the subject. The production of such Indian biogenetic entities lies at the confluence of multiple trajectories ranging from the state, individuals, and the media, to scientific research laboratories, public and private investments in biotech production and consumption [and] transnational research and trade collaborations."

The scientific community in the country also hope to replace the organ trade that India is enmeshed in by "growing organs" in the laboratory. (Aditya Bharadwaj, "Cultures of Embryonic Stem Cell Research in India" in Wolfgang Bender, Christine Hauskeller,



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Alexandra Manzei (eds.) *Crossing Borders: Cultural, Religious and Political Differences Concerning Stem Cell Research*, Agenda Verlag, Münster, 2005. See also Aditya Bharadwaj, "Moral Economy of a Technoscape: The Proliferation of Stem Cell Research in India", monograph, forthcoming).

<sup>42</sup> The Royal Society (the UK's oldest and most prestigious scientific body, effectively the country's national academy of sciences) supported an Indo-UK Stem Cells workshop in April 2005 for British and Indian stem cell researchers. One aim of the initiative was to "a sustained network of stem cells researchers as well as long-term collaborative research proposals between Indian and UK scientists."  
(<http://www.royalsoc.ac.uk/page.asp?tip=1&id=3031>, accessed 28 September 2005)

<sup>43</sup> Ashok B Sharma, "Firms with good track record to get stem cell R&D aid", *Financial Express*, 5 November 2005,  
[http://www.financialexpress.com/fe\\_full\\_story.php?content\\_id=107709](http://www.financialexpress.com/fe_full_story.php?content_id=107709).

<sup>44</sup> For a critique of this argument, see Sarah Sexton, "If Cloning is the Answer, What is the Question", *Corner House Briefing* 16, October 1999,  
<http://www.thecornerhouse.org.uk/briefing/>

<sup>45</sup> John Harris, "Scientific research is a moral duty: Biomedical research is so important that there is a positive moral obligation to pursue it and to participate in it", *Journal of Medical Ethics*, Volume 31, 2005, pp.242-248.

<sup>46</sup> The idea that an individual should give their free and voluntary consent before participating in medical research was first introduced in the World Medical Association's 1962 Declaration of Helsinki. It was prompted in large part by awareness of abuses in medical research carried out in Nazi Germany and Japan, but also in the USA and Sweden.

<sup>47</sup> Donna Dickenson, "Consent, Commodification and Benefit-Sharing in Genetic Research", *Developing World Bioethics*, Vol, 4, No, 2, 2004, p.111.

<sup>48</sup> When Stanford bioethicist Mildred Cho looked over the consent forms for the second South Korean study (after questions were raised about the ethics involved in egg donation for the first study), she found they were still lacking details about how risky egg collection can be. "They [the women] were never told about the risk of infertility or death," she said. In order for the egg collection to be ethical, Cho and her colleague David Magnus say that women need to understand fully both the risks of donating eggs and the reality that their donation may not ever cure a disease or benefit another person.

They also argue that women providing their eggs solely for research should form a new category of research subjects because the usual protections for people involved in medical research do not apply to them. In some respects, they are similar to tissue donors, but unlike blood or sperm donors, they undergo considerable risk because donating eggs is at best uncomfortable and at worst fatal. In other respects, women providing eggs are similar to people who are research subjects, who may go through considerable risk in order to benefit other people or themselves. But egg donors don't really fit into this category, because stem cell research has yet to benefit medically a single person. Moreover, when researchers use anonymous tissues, the research is not considered as research on human subjects, and thus institutional review boards responsible for approving research involving human subjects aren't obliged to approve the consent forms. ("Stanford Bioethicists Want Stronger Protections for Women Donating Eggs for Stem Cell Research," press release 19 May 2005, <http://mednews.stanford.edu/releases/2005/may/eggs-ethics>, accessed 28 September 2005; David Magnus and Mildred K. Cho, "Issues in Oocyte Donation for Stem Cell Research", *Science*, 17 June 2005, Vol. 308, pp.1747-1748.)



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- <sup>49</sup> Ingrid Schneider and Claudia Schumann, “Stem cells, therapeutic cloning, embryo research – Women as raw material suppliers for science and industry”, in *ReproKult* (Women’s Forum for Reproductive Medicine), *Reproductive Medicine and Genetic Engineering: Women between Self-determination and Societal Standardisation*, 2002, pp.70-76.  
[http://www.reprokult.de/e\\_forum\\_3.pdf](http://www.reprokult.de/e_forum_3.pdf)
- <sup>50</sup> *Guidelines for Human Embryonic Stem Cell Research*, National Academies Press, 2005, p.87. <http://www.nap.edu/books/0309096537/html/81.html>, accessed 30 August 2005.
- <sup>51</sup> Donna Dickenson, “The Lady Vanishes, or What’s Missing from the Stem Cell Debate”, *The Ethics, Law and Politics of Human Tissue*, Cambridge University Press (forthcoming).
- <sup>52</sup> Donna Dickenson, “Commodification of Human Tissue: Implications for Feminist and Development Ethics”, *Developing World Bioethics*, Vol. 2, No. 1, 2002, p.61.
- <sup>53</sup> Donna Dickenson, “Commodification of Human Tissue: Implications for Feminist and Development Ethics”, *Developing World Bioethics*, Vol. 2, No. 1, 2002, p.62.
- <sup>54</sup> Donna Dickenson, “Commodification of Human Tissue: Implications for Feminist and Development Ethics”, *Developing World Bioethics*, Vol. 2, No. 1, 2002, p.62.
- <sup>55</sup> Donna Dickenson, “Commodification of Human Tissue: Implications for Feminist and Development Ethics”, *Developing World Bioethics*, Vol. 2, No. 1, 2002, p.61.
- <sup>56</sup> “Morality’s Exchange Rate”, 27 January 2005,  
<http://dustinthelight.timshelarts.com/lint/001513.html>, accessed 14 June 2005.
- <sup>57</sup> Margaret Jane Radin, *Contested Commodities: The Trouble with Trade in Sex, Children, Body Parts and Other Things*, Harvard University Press, Cambridge, MA, 1996, p.159.
- <sup>58</sup> Gerber Fried continues, “In a capitalist context, the idea of choice invokes the marketplace – things that are for sale can be chosen. This neo-liberal notion locates rights within an individual and obscures the social context and conditions needed in order for someone to have and exercise rights. The fact that race and class inevitably circumscribe one’s choices is ignored.” (Marlene Gerber Fried, “The Politics of Abortion and Reproductive Justice: Strategies for a Stronger Movement”, *Different Takes*, No. 38, Hampshire College Population and Development Program, Fall 2005, p.2, <http://popdev.hampshire.edu/projects/dt/dt38.php>)
- <sup>59</sup> Garrath Williams, “Bioethics and large-scale biobanking: individualistic ethics and collective projects”, *Genomics, Science and Policy*, Vol. 1, No. 2, 2005, pp.50-66, p.51.  
<http://www.lancs.ac.uk/fss/journals/gsp>.
- <sup>60</sup> Margaret Jane Radin, *Contested Commodities: The Trouble with Trade in Sex, Children, Body Parts and Other Things*, Harvard University Press, Cambridge, MA, 1996, p.155.
- <sup>61</sup> See Ian Sample and Donald MacLeod, "Cloning plan poses new ethical dilemma: Scientist courts controversy with call for women to donate eggs", 26 July 2005, *The Guardian*.
- <sup>62</sup> Clive Cookson, “The Cloning Connection” in *The Future of Stem Cells*, *Financial Times & Scientific American* Special Report, July 2005, p.A11.
- <sup>63</sup> <http://www.statistics.gov.uk>, accessed 28 September 2005.
- <sup>64</sup> The figures for other diseases that, it is claimed, could be treated with stem cells are less dramatic. About 120,000 people in the UK have Parkinson's disease; about 5,000 have motor neurone disease, the target disease of Ian Wilmut and his colleagues.

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<sup>65</sup> The justification is also given that women with cancers whose treatment makes them sterile could still have their own children – and that younger women can pursue their careers and have children later in life, but with their younger, healthier eggs.

These justifications follow a trajectory that shows itself repeatedly in the expansion of reproductive, genetic and pharmaceutical technologies: get regulatory and public approval and acceptance for a drug or treatment for a medical condition, and subsequently promote it for non-medical uses, which many more people could be expected to take up. Stem cells are already being touted for cosmetic and plastic surgery. For instance, stem cells from aborted fetuses are injected into a person's face in clinics in Barbados, Ecuador, Russia and Ukraine so as to iron out wrinkles. The treatment was initially developed by scientists to treat Parkinson's disease and blood disorders. (Steve Bloomfield, "Britons fly abroad for stem-cell makeovers", *The Independent*, 16 October 2005, [http://news.independent.co.uk/uk/health\\_medical/article320011.ece](http://news.independent.co.uk/uk/health_medical/article320011.ece))

Scientists are trying to create breast implants using stem cells taken from a woman's bone marrow. The beneficiaries are described as cancer patients who have had mastectomies, but women who would like breast or lip enlargements would comprise a larger market. (Nic Fleming, "Master cell' implants to aid plastic surgery", *Daily Telegraph*, 18 February 2005, <http://www.telegraph.co.uk/news/main.jhtml?xml=/news/2005/02/18/wcell18.xml&sSheet=/news/2005/02/18/ixworld.html>)

<sup>66</sup> Researchers are also looking for other sources of embryonic and foetal stem cells: embryos from fertile couples that are not transferred to a woman's uterus because preimplantation genetic diagnosis suggests that the embryo would have a high risk of developing into a person with a certain genetic disease; placentas; and umbilical cords.

<sup>67</sup> Adele E Clarke, "Funding the Reproductive Sciences", *Disciplining Reproduction: Modernity, American Life Sciences and the Problems of Sex*, University of California Press, Berkeley and Los Angeles, 1998, p.207.

<sup>68</sup> Adele E Clarke, "Funding the Reproductive Sciences", *Disciplining Reproduction: Modernity, American Life Sciences and the Problems of Sex*, University of California Press, Berkeley and Los Angeles, 1998, pp.207-230.

<sup>69</sup> For an overview, see Sarah Sexton, "Ethics or Economics? Public Health or Private Wealth?", June 2002, <http://www.thecornerhouse.org.uk/subject/genetics/>

<sup>70</sup> The world market value for stem cell derived therapies (including from adult stem cells) has been estimated at US\$2.7 billion for 2001 (ITI Life Sciences, cited in *Biotechnology Report 2005*, Marks & Clerk (Patent and Trade Mark Attorneys), London, 2005, p.3). But estimates by management consultants Bain & Co suggest that the commercial potential for stem cells is far less than has been claimed. The survey suggests a market of \$100 million by the year 2010, not the US\$10 billion that other analysts have forecast. There are about 140 stem cell related products in development, but the majority are far from clinical trials; of those that reach this stage, many will fail. ("Stem cells and business: Hype over experience", *The Economist*, 22 September 2005.)

<sup>71</sup> "Stem cells and business: Hype over experience", *The Economist*, 22 September 2005.

<sup>72</sup> Victoria Griffith and David Firm, "Stem cell science on a shoe string", *Financial Times*, 18 July 2002, p.11.

<sup>73</sup> Clive Cookson, "Stem Cells: East . . . and West", *The Future of Stem Cells*, *Financial Times & Scientific American* Special Report, July 2005, p.A23.

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For stem cell research, money needs to be locked up for a long time with no marketable products on the horizon. Those with spare money, however, want an economic return within a few years, not a few decades. The free market perspective on such research is illustrative. William Haseltine, the CEO of Human Genome Sciences, Inc and a leading advocate for embryonic stem cells, has said “The routine utilization of human embryonic stem cells for medicine is 20 to 30 years hence. The time line to commercialization is so long that I simply would not invest. You may notice that our company has not made such investments” (quoted by David Weldon in “Federal Stem Cell Research: What Taxpayers Should Know”, *Heritage Lectures* No. 888, delivered 10 May 2005, published 24 June 2005, <http://www.heritage.org/Research/HealthCare/hl888.cfm>, accessed 31 August 2005. The Heritage Foundation is a US think tank “whose mission is to formulate and promote conservative public policies based on the principles of free enterprise, limited government, individual freedom, traditional American values, and a strong national defense.”)

As Denise Pollard-Knight of the Japanese financial services group Nomura International says, “You just have to look at the numbers. VCs [venture capitalists] have invested \$300m to date into stem cell companies as a whole, versus \$20 bn into other technology platforms” (quoted in Nuala Moran, “Touch Cell to Investors”, in *The Future of Stem Cells, Financial Times & Scientific American Special Report*, July 2005, p.A34).

It was lack of interest from the private investment community that closed PPL, the commercial enterprise involved with developing Dolly the sheep, in 2004. PPL was producing human proteins in the milk of animals from which to manufacture drugs, but ran into difficulties when investors wanted to put their money elsewhere. In July 2003, hundreds of PPL’s genetically modified sheep in Scotland and New Zealand were killed. The project came to a halt when Bayer, a German pharmaceutical transnational, said it was putting on hold for at least three years a joint venture with PPL to develop a drug to treat certain lung diseases and possibly slow the progress of cystic fibrosis. One analyst for an investment banker commented, “No one ever doubted the brilliance of their science, but the company did not move quickly enough to commercially viable production. It is difficult to see how they will still be around in a year’s time”.

Simon Best of the UK’s BioIndustry Association, however, attributes the scarce private sector funding to the politically influential minority in the US opposed to stem cell research. Best acknowledges that private investment considers its potential markets first and foremost, the prime market being the United States, which accounts for some 60% of the value of world health care. Unless there is a shift in US public opinion, he argues, “the world’s largest market [for products or therapies involving embryonic stem cell lines] will never open”. (Simon Best, “Funding for stem cell research in the USA and the rest of the world”, presentation at “Putting Stem Cells into Practice: ethical, legal and social issues”, conference held by Progress Educational Trust, 15 November 2005, London, <http://www.progress.org.uk>)

<sup>74</sup> Clive Cookson, “Mother of All Cells” in *The Future of Stem Cells, Financial Times & Scientific American Special Report*, July 2005, p.A6.

<sup>75</sup> “Stem cells and business: Hype over experience”, *The Economist*, 22 September 2005.

<sup>76</sup> On 9 August 2001, President George W Bush did allow federal funding of research on embryonic stem cell lines that were already in existence on that date, some 72 in number. But because of difficulties in maintaining them, they are all now believed to be useless for research.

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The US government does provide “an enormous sum (\$550m) for stem cell investigations by global standards” but because of its restrictions, “the portion for human embryonic stem cell (hESC) studies (\$24m) is only slightly above spending by countries with much smaller budgets where investments go farther”. Private US funding for embryo stem cell research runs to about \$200 million a year. (Sara Beardsley, “A World of Approaches to Stem Cells”, in *The Future of Stem Cells, Financial Times & Scientific American Special Report*, July 2005, p.A20-21.)

<sup>77</sup> The Californian Institute for Regenerative Medicine (CIRM) set up to administer these funds “will develop its own scientific and medical standards” and will be exempt from several “current or future state laws or regulations”. The November 2004 legislation also inserted a new “right” into the Californian constitution: the “right to conduct stem cell research”. In future, the state supreme court could rule that any law regulating stem cell research, including the legislation’s few research standards, could violate this right, and thus be overruled or thrown out.

The Californian funding has already run into problems. It is not clear who would “own” any intellectual property that comes out the research and thus doubtful whether the Californian state would get any share in any profits made, and whether Californians would have access to any resulting treatments. One study concludes that expectations of huge financial and medical returns, which persuaded Californians to vote to spend public money on embryonic stem cell research, are unrealistic and based on overblown analysis. (<http://www.genetics-and-society.org>).

<sup>78</sup> New Jersey: \$11.5 million (another \$380 million proposed); Wisconsin: \$375 million proposed; Illinois: \$1 billion proposed; Connecticut: \$20 million proposed; Florida: \$200 million proposed. (Sara Beardsley, “A World of Approaches to Stem Cells”, in *The Future of Stem Cells, Financial Times & Scientific American Special Report*, July 2005, p.A20-21.)

<sup>79</sup> G. Steven Burrill, quoted in Nuala Moran, “Touch Cell to Investors”, in *The Future of Stem Cells, Financial Times & Scientific American Special Report*, July 2005, p.A34.

<sup>80</sup> Sara Beardsley, “A World of Approaches to Stem Cells”, in *The Future of Stem Cells, Financial Times & Scientific American Special Report*, July 2005, p.A20-21.

<sup>81</sup> The UK is in part concerned that its competitiveness will be affected by developments in the “Wild East”. The governments of China, South Korea and Singapore have made large investments in stem cell research; the research is considered of high quality; and the countries are driving towards clinical uses (*Stem Cell Mission to China, Singapore and South Korea*, [http://www.oti.globalwatchonline.com/online\\_pdfs/36206MR.pdf](http://www.oti.globalwatchonline.com/online_pdfs/36206MR.pdf).)

But one of the scientists leading cloning research in the the UK, Miodrag Stojkovic, who was working with the Newcastle team, stated that it was lack of funds that led him to leave the UK to take up a better-funded post in Spain in January 2006. He commented that Britain was proud of how it regulated stem cell research “but forgot the other important factors, notably financial support”. (Roger Highfield, “Red tape has driven me out, says clone pioneer”, *Daily Telegraph*, 11 October 2005, <http://www.telegraph.co.uk/health/main.jhtml?xml=/health/2005/10/11/npion11.xml>)

<sup>82</sup> The rest of the Europe is more cautious about endorsing human embryonic stem cell research. France has provided public funding of US\$4 million; Germany US\$4 million; Finland US\$5 million; and Italy US\$6 million.

The European Union, although desperately committed to life sciences and biotechnology research, will not at present provide “funding for research that involves human

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reproductive cloning, the creation of human embryos for research (including by means of therapeutic cloning) and research that intends to change the genetic heritage of human beings". It does, however, "allow EU funding of projects involving the derivation and use of hESC [human embryonic stem cells] derived from supernumerary embryos (i.e. embryos left over from in-vitro fertilisation (IVF) that are destined to be disposed off [sic] and for which parents give an explicit agreement that they can be used for research purposes)." ("How does the European Commission deal with ethical issues within its Framework Programme for Research and Development", Reference MEMO/05/121, 8 April 2005, but posted on website 17 May 2005, <http://europa.eu.int/rapid/pressReleasesAction.do?reference=MEMO/05/121&format=HTML&aged=1&language=EN&guiLanguage=en>, accessed 31 August 2005)

The EU has spent about US\$170 million on stem cells over the past three years, but only US\$ 650,000 for human embryonic stem cell research (Sara Beardsley, "A World of Approaches to Stem Cells", in *The Future of Stem Cells*, *Financial Times & Scientific American* Special Report, July 2005, p.A20-21). Despite recently doubling its total research budget, the EU is unlikely to increase funding for human embryonic stem cell research.

<sup>83</sup> Carolyn Raffensperger et al, "Defining Public Interest Research", a white paper written for the Scientific and Environmental Health Network. <http://www.sehn.org/defpirpaper.html>, accessed 31 August 2005. Raffensperger and colleagues point out that:

"A research problem may be posed so that it either falls squarely in the public interest or veers away from it. For instance preventing cancer is unquestionably in the public interest. However, curing cancer is the grayer area, since the primary beneficiaries are not only cancer sufferers but also drug companies who benefit financially from the research. Moreover, the cancer patients who benefit may be those who can afford to pay for the technology, and not the cancer population as a whole. If the research is publicly funded, the unequal distribution of both financial and health gains resulting from the research raises ethical questions."

<sup>84</sup> Henry Etzkowitz and Loet Leydesdorff, "The dynamics of innovation: from National Systems and 'Mode 2' to a Triple Helix of university-industry-government relations", *Research Policy*, Vol. 29, 2000, pp.109-123. p.117, quoted in Kean Birch, "The Genetic Ideology Age: The Bioscience Industry as Self-perpetuating Ideology", paper for the 9th Colloquium of the Postgraduate Forum on Genetics and Society, Cardiff University, 31 August-2 September 2005.

<sup>85</sup> M. Asif Ismail, "Regulating Cloning: The biotech industry pushes its agenda in the states", *The Center for Public Integrity*, 2 March 2004, <http://www.public-integrity.org/genetics/report.aspx?aid=192>.

<sup>86</sup> ISIS, "Academic-Industrial-Military Complex", November 2002, <http://www.isis.org.uk/EngineeringLifeAndMind.php>

<sup>87</sup> See <http://ue.eu.int/en/info/eurocouncil/> quoted in Waldemar Kütt, Etienne Magnien and Mark Cantley, "The role of the European Commission in fostering innovation in the life sciences and biotechnology", *Journal of Commercial Biotechnology*, Vol. 10, No. 1, September 2003, pp. 6-14, p. 7.

<sup>88</sup> The European Union's primary funding mechanism for collaborative Research and Development projects in science, technology and engineering is its Framework Programme. The Framework Programmes set guidelines for distributing budgets between the different research areas over periods of 4 to 6 years; and set priority themes and key technologies that will be preferentially financed. Negotiations are currently underway to set the priorities for

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the 7th Framework that will run from 2007 until the year 2013. The 7th Framework aims to double EU research spending from some €17.5 billion in the current 6th Framework Programme to nearly €40 billion. In the 6th Framework, "Life sciences, genomics and biotechnology for health" were already a top priority, accounting for the second highest spend after "information society technologies". ("How does the European Commission deal with ethical issues within its Framework Programme for Research and Development", Reference MEMO/05/121, 8 April 2005, but posted on website 17 May 2005, <http://europa.eu.int/rapid/pressReleasesAction.do?reference=MEMO/05/121&format=HTML&aged=1&language=EN&guiLanguage=en>, accessed 31 August 2005.)

<sup>89</sup> EUROPEA>European Commission>Research>FP6>Life Sciences, Genomics and Biotechnology for Health, <http://europa.eu.int/rapid/pressReleasesAction.do?reference=MEMO/05/121&format=HTML&aged=1&language=EN&guiLanguage=en>, accessed 31 August 2005.

<sup>90</sup> European Science Social Forum Network (Civil Society Organizations' Alliance for another European Science Policy) *Framework programme 7: towards a real partnership with society?* <http://www.essfnetwork.org>.

Economic gains or profits can be made by some groups even if the research never amounts to any clinical applications, such as new drugs or therapies. As researcher Kean Birch points out, "the biosciences rely on a future-oriented market that enables the generation of short-term value (ie. in shares or venture capital returns) on the back of expectations that there is then no necessity to fulfil." (Kean Birch, "The Genetic Ideology Age: The Bioscience Industry as Self-perpetuating Ideology", paper for the 9th Colloquium of the Postgraduate Forum on Genetics and Society, Cardiff University, 31 August-2 September 2005.)

The computer industry, for instance, has been thriving while helping the biotech industry cope with the flood of information on genes and proteins. The head of IBM Life Sciences says that biotech is "one of the greatest growth opportunities in the whole of IT".

<sup>91</sup> Carolyn Raffensperger et al, "Defining Public Interest Research", a white paper written for the Scientific and Environmental Health Network. <http://www.sehn.org/defpirpaper.html>, accessed 31 August 2005.

<sup>92</sup> Roxanne Mykitiuk, "The New Genetics in the Post-Keynesian State", <http://www.cwhn.ca/groups/biotech/availdocs/15-mykitiuk.pdf>

<sup>93</sup> *Biotechnology Report 2005*, Marks & Clerk (Patent and Trade Mark Attorneys), London, 2005, p.4. The report attributes the discrepancy between Europe and the US partly to the "slightly less liberal patenting regime in Europe" but primarily to delays in the European Patent Office system and uncertainty over the patentability of human embryonic stem cells. The report adds: "The main country in which priority applications are filed, even for non-US applicants, is overwhelmingly the United States, reflecting the importance of the US market and the significance of the US as a source of innovation . . . [T]he next largest amount of filings is made in Japan, although the number of first filings is some 85% lower than in the US. Within Europe, the highest number of first filings is made in the UK, which likely to be the result of a combination of the amount of research performed there, the permissive legislation on stem cell research and the generous patenting regime of the UK Patent Office. The number of first filings is almost as great in Germany as in the UK, indicating that the restrictive laws governing research into and patenting of stem cells in that country have not prevented advances being made in their laboratories."

<sup>94</sup> *Biotechnology Report 2005*, Marks & Clerk (Patent and Trade Mark Attorneys), London, 2005, p.5. "The key applicants for stem cell related patents are . . . not surprisingly, US



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companies or multinationals . . . The University of California has filed 40 stem cell patent families since 2000, primarily specialising in cancer treatments. The pre-eminence of the University may reflect the encouragement given by the Californian state government to stem cell research.”

<sup>95</sup> For more information, see Jennifer Washburn, *University, Inc: The Corporate Corruption of Higher Education*, Basic Books, New York, 2005; Sheldon Krinsky, *Science in the Private Interest: Has the Lure of Profits Corrupted Biomedical Research?* Rowman & Littlefield Publishers, Lanham, MD, 2003. For an exploration of how closer ties between business and university science distort research priorities, see James Wilsdon, Jack Stilgoe, Brian Wynne, *The Public Value of Science: Or how to ensure that science really matters*, Demos, London, September 2005, <http://www.demos.co.uk/catalogue/publicvalueofscience>.

<sup>96</sup> For more information on these processes, see Sarah Sexton, “Trading Health Care Away? GATS, Public Services and Privatisation, Corner House Briefing 23, July 2001, <http://www.thecornerhouse.org.uk>. For an analysis of the effect on women’s health of the privatisation of health care services and of a neo-liberal economy, see Sumati Nair, Preeti Kirbat with Sarah Sexton, “A Decade After Cairo: Women’s Health in a Free Market Economy”, Corner House Briefing 31.

<sup>97</sup> Roxanne Mykitiuk, “The New Genetics in the Post-Keynesian State”, <http://www.cwhn.ca/groups/biotech/availdocs/15-mykitiuk.pdf>

<sup>98</sup> David Cyranoski, “Korea’s stem-cell stars dogged by suspicion of ethical breach”, *Nature* 429, 3, 2004, [http://www.nature.com/news/2004/040503/pf/429003a\\_pf.html](http://www.nature.com/news/2004/040503/pf/429003a_pf.html), accessed 28 September 2005.

<sup>99</sup> S. Okie, “An Offshore Haven for Human Embryonic Stem-Cell Research?” *New England Journal of Medicine*, Vol. 353, pp.1645-1649, 20 October 2005, available at <http://www.genetics-and-society.org/newsdisp.asp?id=869>.

<sup>100</sup> [http://www.technologyreview.com/TR/wtr\\_15889,323,p1.html](http://www.technologyreview.com/TR/wtr_15889,323,p1.html);  
<http://www.abc.net.au/news/newsitems/200511/s1516322.htm>, both accessed 1 December 2005.

<sup>101</sup> Theresa Kim Hwa-young, “Ova donors demand compensation from government”, *Asia News*, 7 February 2006, <http://www.asianews.it/view.php?l=en&art=5322>

<sup>102</sup> Peter Aldhous, “Hwang’s forgotten crime”, *New Scientist*, 4 February 2006, p.22.

<sup>103</sup> Kim Tong-hyung, “Prosecution to Summon Hwang”, *The Korea Times*, 10 January 2006, <http://times.hankooki.com/lpage/nation/200601/kt2006011016543311990.htm>

<sup>104</sup> quoted in Helene Guldberg, “This is like a badly written Greek tragedy”, 16 January 2006, <http://www.spiked-online.com/Articles/0000000CAF22.htm>

<sup>105</sup> “Stem cell experts seek rabbit-human embryo”, *The Guardian*, 13 January 2006.

<sup>106</sup> “Dying can aid stem cell research”, *The Scotsman*, 27 December 2005.