

In the fall of 2006, the UK held a forum on 'Talking about Stem Cell Research' (<http://talkingstemcells.accessall.co.uk>), and my comment was posted 11/22/06, but is no longer available online – therefore please find it below:

Subject: 'Fertility drugs': harm to women/IVF children ignored.

Thank you for the opportunity to comment on embryonic stem cell research (ESCR). My thoughts can be summed up in the following: Would you sanction the plucking out of a neighbor's eyes so that you and/or another could see, leaving your neighbor bloody and blind? Only by denying the considerable permanent damage that 'fertility drugs' have already done to women (and IVF [in vitro fertilization] children) can the analogy be dismissed.

Amidst the US hype, ESCR has virtually been promised as "cures for diabetes, Parkinsons disease, and Alzheimers, etc." - yet women who have been exposed to 'fertility drugs' have subsequently DEVELOPED diabetes, parkinson-like disorders, and memory loss (to name a few). Since hundreds of thousands - perhaps millions - of eggs would be required for research, agents administered to hyperstimulate women (gonadotropins and GnRH agonists/analogs/antagonists) into producing dozens of eggs will be utilized, potentially in overdose mode for maximum production. The risks women will face from ESCR, and the harm that women (and IVF children) have already experienced from these drugs, never seems to be on the agenda of those holding the pens and pennies. How can ESCR have been discussed for so many years without the risks to egg donors being THE central issue in the discussion? Perhaps because fertilists do not like to discuss it.

If injuring women is not of concern to ESC researchers, then I would ask where is your interest to maximize your investment when you seek and utilize impaired oocytes? Lupron, the most "commonly used" fertility agent, has been shown to be detrimental to oocyte quality: In studies in rabbits, egg degeneration was increased. In chickens (where 1 in 25 died), all egg shells had thinned. In humans, "some retrieved oocytes exhibit incomplete nuclear and cytoplasmic maturation after the use of this agonist [Lupron]". In 1994, the US FDA issued recommendations "only pertain[ing] to GnRH analogs" (such as Lupron), and noted: "... the possibility exists that some germ cells may have been permanently affected by drug treatment." The FDA recommendations were. "At necropsy, special attention should be given to the anterior pituitary, adrenal, pancreas, testes, and ovaries, since an increased incidence of neoplasia in these organs has been associated with GnRH agonist treatment." In 1993, a National Lupron Victims Network was formed in the US, and was comprised of thousands of Lupron victims, both from within and outside of the US. The industry wishes to ignore the fact that Lupron is classified as a "hazardous" drug, is categorized as a "reproductive and developmental teratogen", is a Pregnancy Category X drug, and thus has *never* been FDA approved for any form of fertility treatment. Consumers have been 'shielded' from this, and other, information central to an informed decision.

Ignoring facts does not change them. Ignoring the health risks to women from ESCR denies informed consent, negates the risk/benefit ratio, and translates into human experimentation without consent. And without proper informed consent - and mechanisms to compensate women in the event of iatrogenic injuries, including longterm disability - it must be concluded that the field of ESCR is making a conscious decision to deliberately compromise these women's health.

I comment here because of my personal experience undergoing superovulation regimes more than a decade ago, and because of my personal battle with the forces opposing the acknowledgment of health risks to women (and IVF children) from Lupron and fertility drugs - and because I can't envision the present

situation would be any different for an egg donor harmed through ESCR.

In my opinion, a moratorium on egg donation for ESCR does not go far enough ... what is needed and long overdue is a comprehensive, global, retrospective analysis of women and children exposed to these drugs, with policy formulated to assist those already harmed. To further expand this enterprise without such epidemiologically sound study and results, in my opinion, is unethical, immoral, and should be criminal.

Without such safeguards, I would suggest any potential egg donor seek information on her risks from sources other than the industry which stands to gain from her eggs. For medical documentation on the risks of the drug Lupron and fertility treatment, for testimonies of other women who have already been harmed by Lupron and fertility treatment, for further information on the National Lupron Victims Network, and for instances of fraud and victimization within the US fertility industry, please see my 2003 testimony before the US Senate on this subject:

http://docs@commerce.senate.gov/hearings/testimony.cfm?id=685&wit_id=1802. It pains me to add that, since my testimony, I have encountered further health problems, have been hospitalized some 25 times, and am now permanently disabled. My experiences, adverse health effects, and knowledge gained over the last fifteen years should be required reading by every woman considering consent to Lupron and ovulation induction.

To the industry, I would like to emphasize that my perspective has been formed over many years within the US, and it is from these experiences that my knowledge base and sentiments are drawn. However, the only contact I've had relating to the UK is noteworthy in its similarity to my experiences in the US: On 11/1/06, I posted a response to the Daily Mail's report of a woman selling her eggs to pay credit card debt (identifying the health risks to superovulation and providing my testimony's link) - 38 responses, not including mine, were published.

It remains unclear as to what extent ESCR exists outside the arena of the fertility industry. Within the US fertility industry, I have witnessed lack of informed consent, experimentation with hazardous drugs and procedures, off-label promotion (and gross use) of a contraindicated and unapproved teratogen by a "criminal enterprise", conflicts of interest from doctor to opinion leader, deceptive advertising, scientific misconduct, computer alterations, fraudulent studies, deceptive advertising, misinformation campaigns, suppression of facts and risks, and medico legal marginalization of victims, to name a few. If this is the group that partners with ESCR, the considerable permanent harm caused by the drugs required for ovarian hyperstimulation will again be ignored: And the facade will continue that thousands of injured women do not exist.