

House Ways and Means
State House
Boston, MA. 02133

RE: House 2863
July 27, 1998

Testimony in Support of
An Act Relative to the Treatment of Infertility

Dear Committee Member:

As this years session draws to a close, it is doubtful that hoards of supporters have lobbied for the passage of this legislation to regulate fertility clinics. And presumably, the masses that have lobbied in opposition to this bill have been successful in suspending its progress.

To the 25 year old, naive, healthy and fertile Massachusetts consumer undergoing repeated egg donations because she's told the procedure "is safe and without real risks" - and who later becomes infertile, or develops osteoporosis, or cancer, or dies ... you would say what? Would you say "The Committee did not feel that mandated informed consent of the known and suspected risks of assisted reproductive technologies (ART) was important"?

This is the seventh consecutive year that I have provided testimony in support of House 2863. Within my yearly written testimonies submitted to the various Committees since 1992, I have detailed and referenced alarming information from the medical literature regarding the risks and dangers of ART. Given that the legislature is in place to protect health, safety and welfare of the public, it is difficult to understand why this bill remains stalled.

Over the past year, scientists grew a headless frog, prompting the possibility that partial fetuses will be grown to obtain human organs. And the specter of the 'right to replicate' came one step closer with Richard Seeds proclamation he would clone a human within the year. Virtually each and every fertility clinic in Massachusetts (and beyond) has the capacity to perform human cloning attempts ... yet no regulation of the fertility industry? No oversight? No consumer and societal protection??? And one fact omitted from discussion of animal cloning is that the same process of hyperstimulation used in women undergoing IVF is commonly used in the animals: the Industry admits they do not know the long term effects of these agents on humans, yet we're to assume no effects of these hyperstimulation agents on the animals or the resultant product (protein, drug, etc., etc.)?

But we need not even look to the future to find evidence of risk to the public ... it is here now, at your local, unregulated, fertility clinic. These risks are numerous and are

inherent within the drugs and procedures - treatment touted as “safe and effective”. There is little informed consent and there can be none; unapproved chemotherapy agents are being given to healthy women (at nearly 4 times the dose used in men with metastatic prostate cancer); there are duplicitous conflicts of interest; fertility drugs are being bought and sold over the Internet without prescription ... and who is protecting the consumer?

Those in opposition to House 2863 cite the Federal Bill, ‘Fertility Clinic Success Rate and Certification [of the laboratory] Act of 1992’, Public Law 102-493, as “sufficient law and that the Massachusetts bill is merely redundant and unnecessary”. In fact, the Federal Bill makes no mention whatsoever of the clinical aspect of a fertility clinic and addresses only its clinic success rates and voluntary laboratory certification program - unlike House 2863 which mandates informed consent regarding the treatment, the drugs, any alternative treatment(s), and all possible risks and side effects to the patient and potential offspring. The Federal Bill lacks any such language or consumer protection.

The founder of the Boston Fertility Society was quoted in the Globe as saying that “women do not need to know that lupron is not FDA approved for fertility treatment”. The former Director of Brigham & Women’ IVF Clinic (who I cited in my 1995 testimony as having “manipulated figures”) lost his medical license in 1998 after admitting to “falsifying and fabricating approximately 80% of the data” in studies involving lupron. (As a lecturer and lead investigator for lupron and its manufacturer, is it any wonder that this Director suddenly gave lupron “routinely in IVF”, though in the past his Clinic had “only prescribed [lupron] for certain diagnoses.) Who is protecting the patient here???

Where is the protection for the Massachusetts women, children, and men involved in these procedures? If there are no laws to protect the public, then laws are made - right? It is frightening to consider that it is possible human organs will be made from ‘fetal clones for parts’ before laws will be made in the interest of public safety to oversee a fertility clinic.

Informed consent of *any* procedure is vitally important - when you factor in gametes and reproduction, the need becomes even more imperative. As an example of the woefully pitiful state of ‘informed consent’ within ART, I would ask the Committee to consider the ramifications of a letter that I received from a renowned Boston IVF Clinic. This letter enclosed one of their IVF Clinic consent forms for lupron, asking *me* “Do you have 3 or 4 others [side effects from lupron] that would be important to add? ... I don’t think we can add 300 side effects.” That an “expert” would seek this information from me is inappropriate and quite telling of the state of this ‘art’.

The headlines from yesterday’s news regarding the “French government officials who will be held accountable for failing to protect the people” is food for thought. Hypothetically, an attorney might someday represent the aforementioned 25 year old (ill) egg donor ... how would committee members defend their position of inaction? Whose interest is the Committee protecting by failing, for the seventh year in a row, to pass this

bill?

Respectfully submitted,

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