

Statement of Judy Norsigian

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I am Judy Norsigian, the Executive Director of the Boston Women's Health Book Collective (BWHBC), co-authors of the highly acclaimed ***Our Bodies, Ourselves***, now in its 7th edition as ***Our Bodies, Ourselves for the New Century***. Since it was first published in 1970, this widely read book about women's health and sexuality has been read by over 30 million women and many men in dozens of countries around the world. There are now 4 ½ million copies in print in 20 languages, with 10 more editions on the way. For over three decades we have been active in a number of reproductive health and rights issues.

At the outset, let me make clear that my organization and many of our colleagues in the women's health and reproductive rights movements support embryonic stem cell research; but we also believe that a moratorium on all human embryo cloning is necessary at this point in time. It has been disheartening to see so little differentiation between embryonic stem cell research and embryo cloning, so that many people I meet tell me that they thought the two were one and the same. Those of us who are pro-choice want to emphasize that our position is quite different from those who oppose ALL embryonic stem cell research. Many of us support, for example, obtaining stem cells from embryos in IVF clinics that would otherwise be destroyed. Our objections pertain to stem cells derived from embryo cloning. This is a rather significant difference, even though we do share similar concerns with the Catholic Church, for example, about the development of germline genetic modifications and the potential resurgence of a eugenics movement.

In June 2001, our organization joined with other individuals and organizations to produce a widely circulated position statement on cloning. It calls for a ban on human reproductive cloning and a moratorium on embryo cloning solely for the purpose of research. It is signed by over 100 groups and individuals with long and impressive track records working on women's and children's health and is appended herewith. Individuals who worked on this statement include Dr. Paul Billings, Dr. Stuart Newman, Professor Lori Andrews, Professor George Annas, and others familiar to many of you.

1. We believe that cloning technology poses vastly greater risks than other currently available reproductive technologies. It is highly likely that experiments on human embryo cloning would inevitably lead to unacceptable human germline genetic manipulation and pose a threat to many basic human rights. It will be extremely difficult to prevent research on human embryo cloning and related technologies from being used to produce so-called "designer" babies. Germline genetic manipulations would affect future generations in unpredictable and deleterious ways. (I urge you to read the thoughtful and detailed critique by Shannon Brownlee in the March issue of the Washington Monthly.) If we allow research cloning to go forward, it is imperative that an adequate regulatory framework be established first. This is no simple task, and it would undoubtedly require several years to address all the complexities involved. Hence, a primary reason for the moratorium position.

2. Media coverage of human embryo cloning research has largely focused on its therapeutic potential, neglecting the technology's dependence on the thousands, if not millions, of women who must undergo the substantial health risks associated with harvesting their eggs. Of particular concern to us is the lack of adequate long-term

safety data on the super-ovulating drugs that women have to take in order to provide the eggs for embryo cloning. Even though recent data did not find a link between these drugs and an increased risk of ovarian cancer, there are other potential problems with ovarian hyper-stimulation, including possible effects on future fertility.¹ Moreover, this is one area where regulatory controls have long been needed for the IVF field—the need for such regulation and oversight is only heightened with the prospect of thousands more women being solicited to provide eggs for research cloning. We have been among those calling for such regulations for many years and hope that this discussion of cloning will allow us to refocus on the matter of better oversight of infertility services in general. In addition, while some altruistic volunteers may be willing to be egg donors, the reality is that women with limited financial resources will be the primary providers of human eggs to enterprises that offer what appear to be lucrative payments. Furthermore, women who undergo repeated procedures might bear additional risks that are completely unknown at this time.

In recent testimony, one researcher stated that stem cells might be able to provide up to 1.7 million therapies per year. This would require a minimum of 5-8 million human eggs per year - assuming a very optimistically high success rate of 1 stem cell culture out of 3-5 clonal embryos. Thus, it is highly likely that many women will become repeat donors, and that there would be massive expansion in the use of women as paid “egg producers.” We know nothing about the health risks of such repeat donations.

¹ Other risks include severe pelvic pain, rupture of the ovaries, excess fluid in the abdomen and other internal areas, bleeding into the abdominal cavity, acute respiratory distress, and pulmonary embolism.

3. From our consultations with scientific experts in this field, we are convinced that there has been gross exaggeration regarding the current state of embryonic stem cell research. There is still much to be learned in this potentially promising field. A moratorium on human embryo cloning would not halt progress in key areas. Well before embryo cloning research proceeds, much additional work with human embryos is necessary to address problems related to the cancer-causing tendencies of embryo stem cells and problems with controlling how these stem cells differentiate into the tissues needed for therapy. Knowledgeable scientists have affirmed that this work is more readily performed with “standard” embryo stem cells. Thus, the moratorium that we propose will not cause significant delay in this line of research.

4. A moratorium would also allow for other important legal and ethical implications of embryo cloning to be addressed. As Andrew Kimbrell pointed out in his February 5th remarks before members of this body, an unregulated industry in cloned human embryos will likely lead to unacceptable commodification of life. The U.S. Patent and Trademark office has already indicated that cloned human embryos would be patentable, and we have yet to prohibit the sale of embryos or human ova necessary for this technology.

5. If Congress intends to create an effective ban on human reproductive cloning, a careful system of regulation and control over production of all clonal embryos is essential. It should also be noted that regardless of what regulations are created, there are three considerations that will make any enforcement nearly impossible: the privacy of the doctor-patient relationship, the inability to distinguish clonal embryos from

other embryos, and the ready transfer of technology to individuals who would function outside the jurisdiction of regulations.

6. Although we are advocates for a woman's reproductive choice and have worked decades to support improvements in contraceptive research and development, we do not believe that cloning and genetically engineered children are extensions of "reproductive choice." We do not support the extension of reproductive choice into "reproductive commodification" and believe that this technology, if and when it is safely applied, must be narrowly limited to the types of medical conditions and diseases associated with substantial likelihood of death and severe disability in the offspring affected.

7. We need to find ways to support important health and medical research while at the same time maintaining programs and interventions that have already proven their value in terms of saving lives and alleviating suffering. We also need to reflect more upon the fact that many of the newer, more expensive technologies and medical interventions have NOT become much cheaper or even much more effective even after one or two decades of use. Nor have they become even remotely accessible to those who have limited financial resources. In the case of IVF, which has produced over half a million babies worldwide, very few infertile women of limited financial means have had access to IVF services. Questions of justice and equity do not apply to genetic technologies alone, but we need to raise these concerns when setting priorities in the use of public dollars.

Cloning technology, like many other new genetic technologies, needs greater public scrutiny and debate. The public has only just begun to awaken to the possible ramifications of the genetics revolution. Let us proceed thoughtfully and deliberately, put in place the necessary regulations, and be wary of inflated claims made by those with vested interests. Questions surrounding such issues as patenting, genetic discrimination, genetic privacy, and human research subject protections should not be resolved by scientists and biotech corporations alone. As a society, we may decide that some technologies promise, on balance, a minimal positive utility that is inextricable from the threat of unpredictable negative consequences. It will take time to involve the larger public in meaningful debate, but doing so will be well worth it.