

The Politics of Stem Cell Research and Egg Extraction in the United States

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Introduction

Thank you for inviting me here today. It is an honor to participate in this Forum and meet such a dynamic group of women's health advocates. I want to thank Korea Womenlink for bringing me here and for putting enormous work into making this Forum happen, and especially Jeong-ok and Young-Gyung, who were warm and generous in all of their coordination.

It's particularly wonderful to speak on this issue in South Korea, where women's groups have valiantly worked to highlight the health risks of multiple egg extraction, and have stood up for women who were harmed by unethical research practices. You are in a unique and powerful position to affect international public understanding of women's rights and biotechnology, and I am honored to be part of that endeavor with you. I hope that my remarks today about the situation in the United States will contribute to a global effort to promote the health and human rights of women in this new era of biotechnology.

We are all here today because we care about this effort to promote women's health and human rights. With regard to research cloning, we want to ensure the highest standards of health and integrity for women who provide their eggs. Safeguarding the health of egg providers is an international issue, and I am grateful to engage with a group of women who have raised concern from the beginning, far before it entered the international stage and media eye. While scientists are already working on research cloning, it is a very small percentage of all the stem cell research currently being conducted worldwide, and we are within a timeframe where we can affect the course of how women are involved.

The primary question here today is how can we help each other in our work to promote women's human rights as stem cell research advances? The more women's health advocates from around the world can come together to demand just policies, the more likely we are to win. First we need to deepen our understanding of the complex environment surrounding stem cell research in each other's countries.

I want to talk to you today about the politics of egg extraction in the United States. I focus only on the US because that is where my expertise lies, and I will leave a discussion of the politics of other countries to my colleagues here.

I work with an organization called the Center for Genetics and Society in California, in the United States. We advocate for appropriate oversight and regulation of new genetic and reproductive technologies. We support technologies that have positive benefits to society. We are concerned, though, that some new technologies may deepen health

inequities, contribute to further discrimination against people with disabilities and gay people, erode reproductive rights, and create new forms of inequality. My organization is one of very few progressive organizations in the US that is critical of the technologies and at the same time supports stem cell research and women's right to abortion.

In my talk today, I'd like to address four primary issues in the United States: first, the state of human embryonic stem cell research there; second, the connection between abortion politics and stem cell research and the consequent polarized nature of public debate; third, the emphasis on reproductive rights as individual rights rather than human rights; and fourth, the absence of comprehensive national regulation of genetic and reproductive technologies or consistent safeguards for women who provide eggs for stem cell research. I will conclude with our responsibility, globally, as women's health advocates.

State of human embryonic stem cell research in the US

As many of you know, there are different types of stem cell research. Research cloning, the type that requires fresh eggs from women, is only a small percentage of embryonic stem cell research being conducted worldwide, and in fact has never been done successfully. The majority of research is done on embryos created and no longer needed for in vitro fertilization. Criticism of research cloning is often mistakenly understood as criticism of, or even opposition to, all forms of stem cell research. And while research cloning is a small part of the overall research, it is often touted as the most promising. In both our countries, research cloning functions in a commercial environment, in which researchers are racing to be the first to succeed and to gain patents and international acclaim. In the US, conflicts of interest are also rampant, in which many of those who make decisions about oversight and distribution of public funds have a financial or professional stake in the research.

After the scandal involving Hwang, one US researcher was quoted as saying, "The cloning race is back on." This is evident in that at least five institutions in the United States are currently working on or getting ready to begin research cloning. In addition, the state of California is poised to distribute huge amounts of public funds to stem cell researchers. In 2004, California passed an initiative making stem cell research in general and research cloning in particular a constitutional right and allocated \$3 billion in public funds to stem cell research. Due to lawsuits, no funds have yet been distributed, but the Governor recently allocated an additional \$150 million and funding will soon begin to flow. In an environment where scientists are racing to be the first to achieve research cloning, we're concerned about pressures to get enough women to supply researchers' demand for eggs.

As was true in South Korea prior to Hwang scandal, any criticism of research cloning in the US has been seen as an impediment to scientific progress and an obstacle to finding cures for disease. Just last week, the head of a US company working on research cloning commented on the difficulty in recruiting women to supply eggs due to restrictions on payment. He said, "We need to make a decision: Do you want the research to proceed or not?" This question assumes that moving the research forward as quickly as possible is

most important, without consideration for the women involved who must provide the reproductive tissue. The hype in both of our countries obscures deeper concerns about the health of women who provide eggs, the affordability of treatments or cures that might be developed, and the importance of appropriate oversight and accountability of researchers.

US abortion politics and stem cell research

This brings me to my second area of discussion: the political situation around stem cell research in the US and the highly polarized nature of the debate between political conservatives and progressives. Attitudes toward the research are often integrally linked with people's views on abortion. Conservatives who oppose legal abortion usually oppose stem cell research because it involves destruction of human embryos, and progressives who support legal abortion tend to be "pro-science" and support all stem cell research without question. The public debate has therefore been dominated by a focus on the moral status of the embryo and largely obscured other concerns, such as responsible use and societal governance of the technologies and the safety of the egg extraction process for women.

I work with women's health and reproductive rights organizations to raise their awareness about the implications of the new technologies for women, to broaden public conversation beyond the politics of abortion, and to shift the lens through which we view the technologies from an individual rights model to one of human rights. I have heard many US reproductive rights advocates express concern or resistance to government regulation of genetic and reproductive technologies because they fear it will have negative implications for the legality of abortion. My organization is alarmed by the constant attacks on abortion rights and increasing restrictions on women and girls' ability to obtain abortions in our country. At the same time, we know that an unregulated technology industry is likely to have negative consequences for women and girls, and it is possible to build a regulatory framework that supports their rights across many areas, including abortion.

It may surprise you that two of the primary issues my organization has advocated for regarding egg extraction, prohibiting payment to women for their eggs and improving informed consent procedures, have met resistance from some reproductive rights advocates. Some argue that *not* paying women is exploitative, because everyone else gets paid: the researchers, the physicians, the company if a treatment is developed; but the woman who is put at the most risk and undergoes an invasive and time consuming procedure, receives nothing. This argument is understandable, and compensating women for their time and inconvenience would seem reasonable. But our concern, as has been expressed by women's health advocates around the world, is that payment will set up undue financial incentive for economically vulnerable women who would not undergo the process were it not for the money. Many who argue for compensation express an opinion that women should be able to decide for themselves whether to provide their eggs, and prohibiting payment is paternalistic: if women are informed of the level of risk and are fully aware of it, then they should be able to decide whether to undergo the process and compensated if they do so.

The problem, however, is that we don't fully know the level of risk. Egg extraction has primarily been conducted in the context of in vitro fertilization, which is almost entirely unregulated in the United States. Fertility clinics are only required to report rates of pregnancy and live birth and not mandated to report adverse health outcomes. We don't have enough data on long-term consequences of the drugs used for multiple egg extraction. And what we do know is that many women experience, in the short term, ovarian hyperstimulation syndrome, as you know happened to a large percentage of the women who participated in Hwang's research. We also have inadequate data on the drug most often used before stimulation of the ovaries, Lupron. In the US, this drug was approved for other purposes and not tested in the context of egg extraction, for fertility or research purposes. We know many women have experienced adverse effects when taking this drug for endometriosis, and we need more studies to determine its level of safety when used for egg retrieval.

Given our lack of knowledge about the health impacts, can we ensure true informed consent? Women considering egg extraction for research need to be told that the long-term health impacts are unknown, that Lupron was not approved for this purpose, and that the state of the research they are participating in is speculative and in early stages. Here I want to explain another instance where abortion politics affects the politics of stem cell research. Since opponents of abortion rights have been unable to overturn the 1973 court case that guaranteed a woman's right to abortion, their strategy for the last 30 years has been to chip away at women's ability to obtain abortions. One example is their effort to try to legislate specific information that should be included in the informed consent process for women undergoing abortions. Much of this information is inappropriate and inaccurate, and meant to scare women so they will change their decision to abort. The response from abortion rights advocates has been to assert that current informed consent laws are already adequate, and they oppose legislation that would add specific provisions about what should go into the informed consent form.

When my organization suggested that legislative safeguards for women providing eggs for research should include specific provisions in the informed consent process, we were challenged by abortion rights advocates who were concerned it would set a dangerous precedent for abortion legislation. You can see that navigating legislation involving reproductive material or tissue is very tricky in the US. Obviously we do not want our work to be used by anti-abortion efforts to undermine women's rights. This is an instance where women's health advocates have been at odds even though we share the same end goal: to preserve and promote women's health and reproductive rights.

Because of the constant attack on abortion rights and because of inequities in the health care system in the US, most reproductive rights organizations have been pushed into a defensive position about reproductive health issues and have not been able to get involved in the complex and challenging discussions about genetic and reproductive technologies. Some groups with a broad understanding of reproductive rights, however, are beginning to engage with these issues and ask questions about equity, justice, and human rights. In particular, women's health organizations who work with women of African, Latin, Asian, and Native descent and have a deep understanding of how

discrimination impacts women's health and integrity have a greater tendency to understand biotechnology's potential for increased commodification and exploitation of women and their bodies.

Among groups who oppose abortion, a few have begun to address issues of women's health related to stem cell research. Some advocates who support abortion rights, including several of our allies, have developed alliances with anti-abortion groups to show unity among groups that usually do not work together in an effort to strengthen political force on this issue. My organization has chosen not to work with anti-abortion groups because we feel that such an alliance is not a productive strategy to follow, due to the divergent nature of our broader goals. Instead, we are trying to mobilize the reproductive rights and women's health movements to take on the issue of egg extraction in particular and engage with the larger issues of genetic and reproductive technologies in general. Our estimation is that an alliance with anti-abortion groups will only serve to alienate us from our usual allies in progressive movements.

Reproductive rights as individual rights

This brings me to my third issue: in the United States, the right to an abortion is viewed as a matter of individual autonomy and privacy from government intrusion. A woman's right to make her own decisions and not be restricted by the government is a central tenet of reproductive rights. This tenet is certainly critical for women's self-determination. Yet the overall individual rights framework in the US is inadequate to give us tools or frameworks to determine where to draw lines and truly safeguard and promote women's health, safety, integrity, and ability to exercise our rights.

In the case of stem cell research, I would like to make a case in the US for placing reproductive rights within a human rights model: it would not just include a woman's ability to make her own decisions about whether to donate eggs, but more broadly encompasses the right to expect that the egg extraction process has been deemed safe before being asked to go through it, the right to expect that less risky alternatives have been tried and exhausted first, the right to full access to information about the process and, if that information is not available, it be obtained before asking her to undergo the process. Guaranteeing reproductive rights in the context of stem cell research requires a shift from an individual rights model, in which autonomy in decision-making is the primary focus, to a human rights model, which demands the highest standards for health and dignity. A human rights perspective encompasses the right to make autonomous decisions, and provides a framework to promote the well-being of global society.

I am grateful for work in other countries and integrated international efforts that have framed reproductive rights as a human right, and reproductive rights advocates in the US have a great distance to go in learning from our sisters around the world and shifting our framework.

Absence of comprehensive national regulation

We arrive now at my fourth and final issue: the US is far behind other countries in developing comprehensive national regulation regarding new genetic and reproductive

technologies. There is little national regulation of stem cell research in the United States. In 2001, one of President Bush's first moves was to limit federal funding for embryonic stem cell research to those stem cell lines that already existed. Here you see a primary example of abortion politics: Bush opposes legal abortion and sees it as the destruction of human life, believes embryos are life and deserving of legal protection, and therefore opposes research on human embryos. I'm sure you are all aware that he recently vetoed a bill that passed the US Congress that would have allowed federal funding to develop new embryonic stem cell lines. This bill had support from legislators within both political parties and its passage would have led to necessary discussion of proper oversight of stem cell research.

There is a stalemate around embryonic stem cell policy at the national level because politicians cannot get past their positions on the status of embryos and whether it is morally acceptable to conduct research on them. The result is we have no national regulation of stem cell research. National guidelines were issued by the National Academies in April 2005, but they are only recommendations. It is an important milestone that these guidelines were issued, but the problem is that they are voluntary, there is no official body overseeing their implementation, and no repercussions for violating them.

In response to prohibition of federal funding, several states have passed their own laws or held ballot initiatives to support embryonic stem cell research. The constitutional amendment passed in my home state of California that I mentioned earlier passed through a ballot initiative, in which citizens got to vote on it. The initiative established an Institute to distribute the public funds and exempted the Institution from state oversight, even though it is funded by state money. The oversight committee established within the Institute has been riddled with conflicts of interest. My organization opposed this initiative because of concerns about accountability, transparency, appropriate oversight, and the health of egg providers, and we have been instrumental in raising these concerns with the Institute since the initiative passed.

The Institute's oversight committee just adopted regulations in August, but they only apply to researchers using public funds they distribute. Researchers using private funds have no binding regulations to adhere to. Because of this, my organization and a few others in California have been working closely with a Democratic State Senator's office to pass legislation that would establish regulations for privately funded stem cell research involving egg extraction. I mention this to show how much we have a patchwork of regulation rather than comprehensive policy, even within one state. The law easily passed the state legislature and is now awaiting signature from the Governor, which we expect by the end of September.

South Korea, the UK, Canada and several other countries all have national laws addressing the use of eggs, sperm, and embryos. This is a comprehensive approach establishing oversight of all genetic and reproductive technologies. Unfortunately, and you all know this better than anyone, we know these laws do not necessarily prevent abuses. But putting them in place is an important first step. In the United States, policy is

being developed state-by-state and only addresses embryonic stem cell research. It does not address eggs, sperm and embryos for fertility purposes, even though this is an area that severely lacks regulation as well, and which requires attention from women's health advocates.

My organization and a few other progressive ones have been working to reframe the debate around research cloning and focus on broader ethical and political issues: guaranteeing the health and integrity of women who provide eggs for research; guarding against research cloning from leading to human cloning or genetic engineering; and assuring appropriate oversight, regulation, and accountability for those conducting research cloning. When research cloning first started, we questioned whether scientists should be asking healthy women to go through a risky procedure for speculative research. This is a critical question and one that some women's health advocates are still asking. Now that scientists are moving forward with cloning research, my organization has shifted our position to demanding assurance for the highest standards for health, safety and accountability.

Conclusion: responsibility of women's health advocates

In conclusion, I ask: what is our responsibility as women's health and reproductive rights advocates to ensure these high standards? We must demand that women's health advocates are involved in setting priorities for research; that women's health and rights are a central focus of any research; and that women play a key role in setting regulations and laws governing the use of reproductive material. We must demand investigation into alternatives to egg extraction so that young women are not asked to "advance science" at their own expense; demand studies on the short and long term health impact of drugs used during multiple egg extraction to determine their level of safety; and demand the highest level of safeguards be put in place to minimize the risks to women and prevent exploitation.

Korea Womenlink and many of you here have been doing this work already. You were doing this work before the news broke about Hwang's ethical breaches obtaining eggs. Korea Womenlink has brought all of us together here today to strengthen and broaden our work to safeguard the human rights of women in this new era of biotechnology. We have a big challenge, different in our respective countries, depending on the politics, the laws, and the cultural norms around women's health. But the boat on which research cloning sails has only just left the harbor. It is still within our reach. We have the opportunity, the knowledge, and the power to join together to change its course.