IMMORTAL CELLS, MORAL SELVES: THE ETHICAL CONSIDERATIONS OF HUMAN STEM CELL RESEARCH*

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I. INTRODUCTION

Genetic research, in its determination to seek out the fundamental answers to human biology, has dominated scientific debate for the last fifty years, since Watson, Crick, Wilkins and Franklin first caught glimpses of nuclear DNA.[1] Thus, human embryonic stem cell research, research that fully utilizes the insights and essential framework of genomics, but seeks to understand

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1 Watson, James, *DNA*, Press, 2003, Introduction, and pps—.

far more about how cells signal, repress, express the proteins that shape then, emerged as a part of the larger series of intellectual and social debates about molecular biology, human genetics and medicine. The debate about the meaning, telos, and nature of the work thus takes place on several levels of discourse simultaneously, signifying and symbolizing a great deal more than the mechanics of method, as do all great debates in science. Turning points in human understanding, such as Copernicus, Galileo, Newton, and Darwin, are always multiplied layered, for they lay claim to the largest subjects of knowledge-the central subjects of moral philosophy-what is the nature of life itself. Claiming to deconstruct and define such answers has been problems in the domain of ethics and religion, for the science remained frustratingly speculative. As each part of the puzzle of humanness, being and behavior is unraveled by biology, however, it threatens the power to name and define the whole. Hence man core issues and definitions are first contested, and then largely ceded to biology by the late the 19th century. The present ethical and moral debates on stem cells make a collective sense of unease about such definitions about a new frontiers-how ought we become witnesses and interpreters of the transformation of the earliest stages of the human embryo?

At this stage, and in the largely secular pluralistic world of the academic science community, one is lead to ask: Why do religious and philosophical arguments so dominate the debate on stem cells? What is the warrant for listening to such ethical arguments in biology? Should science be a matter of politics or ethics at all? In this chapter, I will give an account of how this came to be the case, summarize the leading arguments held by different sides in the debate, describe the policy options engendered by the different moral appeals, and suggest an intermediate normative approach.

II. THE TASKS OF BIOETHICS

First, it is the essential work of the field of ethics to delineate, reflect upon, consider comparatively and then justify and different moral appeals, asking questions about the nature, goal and meaning of the moral activity, and finally asking what of many possible acts is the right act, and what makes it so? As a field, ethics is of particular use when several competing moral appeals seem justifiable. In stem cell research, in a global scientific world, and in the twenty first century, much of what had been previously agreed upon is a subject for debate, for we share a pluralistic society, a new science, and true moral uncertainty about the limits of nature and the nature of limits. Religions have become central to the debate because they offer one consistent set of moral rules that, within the perimeters of each community, have at least a common ground. Ethics is about how we reflects when we are decidedly not on such common ground, on issues at the margins of the grounds, and in contention. Ethics is largely border negotiations. Further, the debate about stem cells takes place at the junction of several social discourses: policy, science and ethics, and no one field can claim perfect rhetorical authority. In the past, debates about such things as moral status, as in the great debates about slavery or just war, was mediated by the dominate church, and by the state, either with political or finally, military means. But in a society where churches and states do not have hegemony, the debate is far more complex —it assumes a new character— a free standing debate about the ethics of each act.

III. ETHICAL DEBATES AT THE UNCERTAIN BORDERS

We are collectively uncertain about the role of religion in public life. There is a wide understanding that the United States Constitution prohibits the establishment of any state religion, but what of good argument that emerge from faith traditions-should

they be any more or less privileged than ones that emerge from tradition of philosophy, such as Kant, or Aristotle? What should the role be for the widely used term "moral repugnance?" if an act is strongly repellent in one religious community, but not in another?

We are confronted with scientific uncertainty as well, and ongoing debates about what stem cells are, and what they might do. Are adult cells able to be reprogrammed and kept immortal? (And to what ends might that eventually lead?) Are embryonic cells, somehow cached in body? What is the mechanism in cell biology that differentiates the cell-how does "stemness" work? Embryology is still not fully understood, nor is the immune cascade response, so important if medical researchers are to confront the problem of using the cells for tissue transplantation, not is there full agreement on the role of the cell as a signaling system.

We are confronted with uncertainty in our national —and certainly any international- science policy. Who should make and then monitor such policy and what is the scope of its power, and what is the right approach for a normative policy?

Policy statements conflict with each new commission, national organization, and science board deliberates. National Academy of Science[2] issues reports on both stem cells and, when it was suggested that human "cloning" or somatic cell nuclear transfer (SCNT) would be a reasonable way to address issues of tissue incompatibility and a useful initial step in research on differentiation, another report on SCNT. Reports on SCNT (research cloning) from California Cloning Commission[3] in 2001 took up the issue of stem cells. Such uncertainty lead to a Congressional debate, in which the House of Representatives passed a bill in august 2001 (265-162) which banned and criminalized the research on, the making of tissue or prod-

2 NAS, *Report on Human Embryonic Stem Cells*, 2001.

3 California Cloning Commission, *Report on Human Embryonic Stem Cells*, 2002.

ucts from human embryonic stem cell, the use and the import of any products from that tissue. The Senate considered a complementary bill, the Brownback Bill in June 2002 but did not come to a final resolution as august, 2003, when they were faced with widespread opposition to such a bill, from 70 Nobel Laureates, the American Association for the Advancement of Science, scholars in religion and ethics, and over 100 Deans of Medical Schools. The AAAS and the Hastings Center offered reports in 1999. The National Bioethics Advisory Committee, appointed by Bill Clinton to advise him of bioethical issues, supported the use of human embryonic stem cells in research, (1999) and the limited use of embryos to produce them, the NIH crafted a compromise in late 2000 to allow the use of stem cells but not there derivation, a policy taken "under advisement" by the president. After the election of George W. Bush, a new policy was proposed. President Bush's attention was turned fully to the debate in his first months in office, and it was the subject of his first public national address august 9, 2001.

It is not only policy that is in flux, the very polity is uncertain about its role and voice in the debate. We are an american polity with disagreement about the role and reach of the State, we are a polity rocked by debates about family and reproduction, a polity with complex and competing structures for apprehending illness, aging and death, a polity with competing moral understanding of the nature of the good act and a polity in debate about life's beginnings. Health care since the AIDs epidemic has been shaped in large part by patient advocacy and consumer groups, a new force in the debate. Should patient advocacy matter? What role should activists play in promoting of research, and should such advocacy groups have, as many argue, a larger role in the debate because they bear the costs of disease most directly and vividly?[4]

[4] As was the case made at the International Society of Stem Cell Research First Annual Meeting, Washington, D.C., june 2003, by an activist from the Christopher Reeves Foundation.

How do we construct and defend our arguments in civic discourse (in public protests, in Senate hearings?) What is the role of the state as a mediator when citizens disagree seriously, and are ready to go to extreme measures to defend their position? (which is as fierce in these debates about moral status of the embryo as earlier american civic debates about the Civil War, Civil Rights, and Roe v Wade).

Making the debate around the ethics of research on human embryonic stem cells ever more intense and divisive is the suggestion that "cloning", or somatic cell nuclear transplant (SCNI) as a technique should be allowed as a part of the research, thus wedding two of the most volitible issue in medical research-how we ought regard the human embryo in its earliest stages, and how we ought to set limits on our capacity to create human replication, a debate already strained by the explosion in advanced reproduction technology.

The research about the creation of life was not, to be sure the only new biomedical and bioethical frontier in genetics. There as been an explosion of genetic knowledge about the etiology of disease, aging, and thus about the new field of regenerative medicine, including its efficacy and its appropriateness. Safety concerns haunt all new research, and the decade was further shaken by dramatic defeats in human gene transfer, further confusing the public about what claims of research could be trusted. Even the tantalizing premise of tissue engineering, even hopes for tissue transplantation, the cure for degeneration diseases, for genetic disease for autoimmune diseases, for understanding embryologic development and for teratology and for understanding cellular reprogramming, growth and death seemed still largely theoretical. There were several serious problems in application. How to make histocompatable tissues for recipients created several new ethical dilemmas. For example, if banks of stem cells from many different DNA sources where created, how would donors be recruited fairly? If a universal cell could be created, what was the assurance that genetic alteration would be stable, or when tolerated? If

chimerism/partial toleration was used to introduce new tissue into a recipients body, as it is in adult tissue transplants, and whole organ transplants, how would the side effects be addressed? If SCNT-cloning-was used, how would (nefarious) scientist be kept from trying to create humans, as fringe group scientists kept threatening to do throughout the debate.[5]

The polity erupted in controversy, which became political, yet in unusual ways, with opponents and supporters from all sides of the political spectrum. The American Heart Association rescinded its initial support of stem cells after Catholic donors expressed concern and withdrew support for AHA funding in this research. Prominent leaders on the left, such as ecologist William McKibben, and William Kuchinic, opposed the research, while Nancy Reagan, Orrin Hatch, Arlen Spector and others traditionally of conservative leanings come out in public support. Like political leaders, religious groups differed in their approach. For Islam, Jewish and liberal Protestant scholars, the research was either permissible or mandated as a positive act of healing, and the embryo as lacking full moral status as a person. For many roman catholic and evangelical protestants, the moral status of the embryo as fully ensouled at the moments of conception readered acts of research on it as a violation, and its loss in research was regarded as the murder of a human being. Genetic research had already queried matters about the boundaries of life and our warrant and providence, and stem cell manipulation was seen merely as an extension of this hubris. For many, the controversy represented the first time since the discovery of recombinant DNA technology that research was seriously questioned, and its future course at stake. Many raised the argument of the outsider: Because of the separation between Church and state, the faith communities and other dissonants felt it was reasonable to stand as outsiders to the debate, and held this outsider status as unique perspective. Patient advocates claimed otherwise, asking for

5 See *New York Times*, section A, december 23, 2002, on the Raelians.

their status to be taken more centrally, as persons most affected, and finally, scientists themselves called for the debate to be located primarily, or a led by those within the academic scientific community with the most expertise in the actual science at issue.

IV. "There may be valuable scientific knowledge which it is morally impossible to obtain…"[6]

When the christian moral theologian Paul Ramsey made the arguments for limits on our knowledge, he was in part concerned about genetic research, asking scientific researcher to first ask ethical questions —What is the proper object of our desire? What can one trust? In this, he was assuming that science is embedded in communities of responsibility for science's implications bear upon us all, hence we all participated in them and had a right and responsibility to comment on them. In response to such early contentions in clinical research and clinical medicine, bioethics committees, and bioethics for a began to emerge as alternate venues for moral debate. For example, after the family of Karen Ann Quilan went to court to gain permission to withdraw her from a ventilator that was keeping her alive, the NY State Commission on Issues at the End of Life debate the policy to regulate such matters, and when the mapping of the human genome was proposed, funding was set aside to allow ethics discourse and research to continue mapping the ethical, social, and legal issues raised by the science (ELSI Projects.) Ethics has been a potent force in the debate since Ramsey first raised the question.

V. Forbidden knowledge

In several critical ways, research on human embryonic stem cells recapitulates old arguments about our faith in science, prog-

6 Paul Ramsey, 1970.

ress and technology. Science in general, and genetics in particular lays claim to topics that are by their very nature controversial because they are simply new to our established normative narratives, raising some to claim that we are "moving rapidly toward a post-human future". In some ways, research raises fears about forbiddenness, and newness itself, and in other ways it potentiates fears about violations of "mother nature" an argument that is engaged both by fundamentalists and environmentalists. The forbidden nature, or the speed of research is part of a larger debate about modernity and its uses, a debate waged around many other new knowledges: anesthesia, vaccination, electricity, among others.

Further, new knowledge is threatening to an established order, and to the nature of order (and the order of nature) that is envisioned as reflected in the nuclear family. Many have been most adement in their opposition to research on embryos, or research in molecular genetics because they have felt it destabilizes families and natural reproduction. Hence Leon Kass has argued against stem cells because it may cause "moral harms" toward the family.

This idea of a lost, beneficient, natural order, in which nature is seen as normative, is a familiar one in philosophy and in political life. In philosophy, Nietzsche, and Heidegger both argued that modernity, science and the social contract of the modem state distanced "man in his essence", a more authentic man, from a creature he was forced to be in a technological word, and called for "a more primal knowledge" as a basis for their ethics. In many religion(s), the same period that has witnessed fierce opposition to science, has seen a rise of fundamentalism(s), a questioning of evolution, and a rejection of facticity. In politics, a fear of the future has often tended to replace an earlier optimism about the future. And in all of these arguments, the return to the past, or an imagined past is attractive, and salvatic. It is against this strong cultural yearning that the first research on human embryonic stem cells was cast and it is in part why the reaction to this last in

a series of experiments has catalyzed such attention toward the question of the essential morality of such research.

VI. Four sets of questions about the ethics of research

In regarding the answer to this question: what is the right act, and what makes it so? Ethicists have classically turned to four types of problem. What are the origins of the materials used in research (issues of moral status); what is the process by which the material are obtained and manipulated, what is the telos, or ends of the work, and what is the social context into which the work enters and exists? In regarding this questions, ethicists begin with two classic taxonomic tasks —two types of questions, that sort and define the problem, that of definitions and that of norms, or rules of action, on which policy and legal issues emerge. Epistemic questions (how do we even know what we think we know) always dedevil philosophy, and they abound in stem cell research, where the science is new, and subtle. What counts as a truth claim? What language can we agree on when we define things? How do we define life, or suffering, or goodness? Who is "we" and does our community include such being as embryos, or "children yet to be born" or "die patients of the future?".

Normative questions also mark the debate: Whose truth claim wins out when many compete? How do we regulate research? How do we enforce regulations? How could we control the process and outcomes? What is the role of the State in science policy?

1. *Origins*

A. *What is the moral status of the blastocyst?*

Since this question has dominated the controversy about any sort of research on embryos, and in particular, for stem cell re-

search, let us turn to this. We are asking different sort of questions. First, what is the essential nature of these cells? And second, what are our duties toward the blastocyst? Hence, if the cells are fully ensouled humans (like newborns) one needs to regard them as such and one's duties to the cells are morally equivalent to duties toward any other dependent vulnerable human. If they are regarded as tissue of worth, (like hearts one can transplant) one has duties such as respect, care, or prudence to consider, and if they are regarded as tissue that is like any other body tissue, or like tissue to be discarded (like placentas), they our duties are largely that of attention to the symbolic dignity of anything human.

B. *When does life begin?*

Human eggs are alive (in that they are not inanimate objects, and in that they are cells with the ability to divide.) All eggs are potentially fertilizable. Brigid Hogan as noted that when "life begins" is a complex question —think of a blastocyst as origami paper, she argues, which needs a genetic signal to be folded correctly.[7] This signal one in a cascade of biological events, could be one mark of human life, but one could point to other moments within the activity called "fertilization" in 19th century terms. Moral status is contended ground, and can be defined relative to many factors, including when biological individuality is established, when, a certain level of organization is achieved in the blastocyst, by standard temporality (ranging from 1 second to 40 days of maturity), by the reason for creation and existence of the embryo (intended to become a baby, or intended to be used for research, the physical location of the embryo (in the womb, in a test tube), the potentiality of the embryo, the likelihood that is it destined for destruction, or as some have suggested, by determining the rates of loss in human reproduction of all embryos (close to

7 Hogan, talks at Vanderbilt University, october, 2001.

90%). Since moral status has been important in politic/religion/legal systems for centuries,[8] and since a pregnancy was not perceptible to the external world of the polity for months, most textual traditions which are rooted in antiquity assume an ancient tradition of an "unformed fetus". Such a term is found in the writings of Aristotle, in both the Hebrew Scripture and the subsequent talmudic discourse, in the Sharia, or Islamic legal commentaries that interpret the Koran, in Augustine, in Thomas Aquinas and until, 1859, the Vatican held the interpretation that until 40 days into the pregnancy, or until (for Muslims) the bones has "knit", or (for the Aristotelian tradition) the menstrual blood has "congealed", a embryo had a null to limited moral status. In Canon law (the Catholic legal authority) this idea held until 1917, when, following the new science that could observe eggs and sperm, the idea of a homunculus at the head of a sperm being implanted like a seed in the women was dispealed. Most theologians until late 19th century had an idea the pregnancy was not an established and protected fact until this time and ruled on cases, and wrote as if this were indeed the case. Recent debates may tend to obscure this history, but the idea of personhood beginning at "the moment of conception" is a relatively new idea, one that has changed dramatically from earlier perceptions.

C. *Linguistic uncertainty and narrative uncertainty*

The central concern about moral status, however, has lead many to think of the ethical issues of stem cells as one synonymous with abortion, and this has lead to the use of similar language in both debates: women's rights, babies, fetuses, reproduction, choice vs. life. It is not the only linguistic uncertainty. Several have raised

[8] For matters of compensation in the loss of a pregnancies, for issues of when and under what circumstances a community mourns for the loss of a pregnancy, etcetera. Devid Feldman Abortion and Birth Control in Jewish Law.

the issue of whether an artificially created, or a very early blastocyst is properly called an embryo, or whether this term confuses the lay public. The use of the term "cloning" is a further problem, since the goal of human or animal cloning is to produce offspring, but die goal of "cloning" for research is to study how very early development occurs. Narrative uncertainty has also been introduced into the discourse. By this I would argue that there has been a break in the outstanding cultural story of the nuclear family, the miracle of birth through loving sexual intercourse. Significant changes in the essential and primal narrative of human reproduction have raised the question What is a family now? What does it mean to make embryos with a series of unions of parts from variable sources? What if the narrative has alternate possible endings? The traditional narrative of human reproduction —one man, one women, a meaningful Adamic cleaving, leading to progeny that carry the story forward— is at the heart of many faith traditions. Indeed, it is through this human story that Western traditions, and several of the traditions of Eastern and indigenous religions[9] create a core narrative about the meaning, nature, and goal of being human.

Our understanding of ourselves as a part of this narrative, as children and then parents, undergirds the meaning of many theological constructs: natural law theory, the begotteness of children, the pronatalist imperative, and the obligations and relationships in families and communities. However, since the early 1970s, the idea of the natural process of sexual reproduction has been disrupted by emerging scientific technology, which has created many possible origins for any human embryo: it may be fabricated by mixing eggs and sperm, or by injecting an egg with a selected sperm. The course of development may be altered as well. Sperm may be "spun" and separated by weight to select for gender; the egg may be altered, with extra mitochondrial DNA;

9 Variants include heroic or divine-human conceptions, but all are based on sexual union, gestation, and birth.

embryos may be deselected by genetic trait; the embryo may be implanted in a surrogate, the egg obtained from another women, and the resulting child given to a third family, which may itself be constituted in a variety of genders and permutations. All of these disruptions in the core narrative have elicited considerable alarm initially, and at each stage, social discourse has emerged as new possibilities are discovered, and in many societies, the narrative has been re-imagined, and retold, to account for these new possible narrative But regenerative medicine offers not only another set of beginnings for the narrative of reproduction, but other possible telos for the embryo. Now, a blastocyst fabricated in an lVF clinic faces at least four fates: it might be transferred to a human womb, where it might implant successfully; it might be transferred, but not develop, it might be frozen; or it might be discarded. Alternatively, the embryo might be destroyed in a lab in the process of being used to make stem cells. Once our society allowed for the first four outcomes, the last, in the lab, can be understood as an alternate ending or alternative goal. For many, such a deconstructed narrative, with the possibility of origins other than monogamous union and ends other than reproduction, elicits a sense of moral repugnance, the ultimate horror of a scientific, desacralized world. But for others, this revised narrative elicits—a curiosity and awe at the new possibilities for human understanding, and of the possibility to alter other key aspects of what had been understood as moral fixities-the nature and scope of human suffering, the "natural" span of a human life, the capacity for human reach.[10]

[10] I wrote the first drafts of this paper and delivered the speech on which it is was based prior to reading the seminal work on this central idea, Roger Shattuck's Forbidden Knowledge (1996). Harcourt Brace, and Company, San Diego, 1996. T.

2. *The process: human subject issues*

How can the cells be obtained and created justly?

Ethical questions have not only emerged about the moral status and origins of the tissue, but from the "harvesting" of the gametes needed to fabricate the blastocyst. All eggs come from a particular woman, all sperm from a particular man. How are these obtained justly and safely from human subjects-does this change if the women and men whose gametes are at stake are voluntarily (even desperately) trying to achieve a pregnancy, and in so doing create "excess" embryos they do not choice to use? Dresser and others[11] has raised concerns that women might be exploited or manipulated into using their bodies to make money, and be placed at undue risk if they are hormonally stimulated to produce eggs.

Others have raised epistemic issues in the process. What does it mean to "make "embryos with a series of unions of parts from variable sources? Will such a dissaggregation of the pieces of the person lead us toward a world of commodified, exchangeable selves-a sort of warehouse supply store which would cheapen unique human lives? Would disabled persons be seen as poor products, and be discarded as some have claimed? What are we to make of the practice-already in place-of advertising for gametes from women of privileged social or intellectual status, and competing for the "best eggs?" Since marketplace relations have, in the past, understood women's bodies as at least potential commodities, what protections might be instituted to protect human subjects from the pressures of the market?

A second problem in the process of the design of all biological research is that one cannot made a model of the problem, as one can in other sciences. Unlike physics, the model is the actual event. There is "No truth but the thing itself". Hence, even making models creates the problems one needs to tentatively explore.

[11] Rebecca Dressor, in Report of the Presidents Council on Bioethics, 2002.

A third problem is the slippery slope issue, or the "trigger" problem, in that event making and perfecting a small part of the technology that can be use for cloning, or genetic engineering, can allow a desensitization to the next (troubling) step of the science. Here, the concern is that setting up a project that allows for "harvesting" of gametes, cloning, etcetera, would set the stage for cloning for reproductive purpose, or genetic engineering for "designer" babies, or other such scenarious.

A final problem is a structural one. In the past, the public understood research on embryos as instrumental toward the goal of reproduction (hence the support of IVF research). Here, the process itself is geared toward a more abstract telos, and hence the charge arises that embryos in this case are only being made to be destroyed. If embryos are uses that are intended to be discarded, and have been created for reproductive purpose, then for many, their use in research is an event that occurs along the way of the inevitable trajectory toward destruction, which is a different ethical category than embryos newly created for research. Yet it is precisely this sort of experimental use that promises to yield important understanding of early stages of cell signaling, cell programming, and genetic control mechanizes, in both normal and disease states.

3. *Telos: Creating a moral policy*

How do we construct a world of human flourishing?

Thinking about the ends of the research on human stem cells has initiated a discussion on the nature of the ends and the goals of health care itself and lead to a critical split in how we considered aging, human frailty and illness. Kass, Meilander, Fukayama, and others[12] have raised serious concerns that if the goal of this re-

[12] See, The Presidents Council on Bioethics, july 2003, also see Kass, Leon and Fukayama, Francis—, 2003.

search is to eliminate illness, or human suffering, it is a flawed goal. Kass has spoken of the character-builing engagement of live lived well as one ages, of lessons learned via the suffering and subjection of the creaturely body, and of the virtues enhanced with the acceptance of even serious disability. What will happen, ask these critics, to our sense of compassion if its objects — vulnerable, frail and elderly, are enhanced to robust cheerfully perfection? Yet others, such as Stock, Silver and Caplan, disagree,[13] arguing for a world progressively liberated from such limitations. Others have raised issues of unintended consequences-unknown and unknowable chaos that may result if this research is pursued. Clearly, since the fact that we are witnessing only the very earliest stages of research means that while interesting, are still largely theoretical, the civic discourse will have to both attend to such concerns, welcome them, and yet attend to the immediate issues of how investigators need to act now to structure such attention should such choices ever confront us.

4. *The Contextual Framing of the issues*

Can just research be conducted in a world of injustice?

The context of all research is the health care is an unfinished project of social justice. In American, the uninsured with minimal access to basic health care continues to vex political policy. International issues of distributive justice tender the problem of access to new research and the therapies that will emerge from such research as a central ethical concern. Moreover, as noted above, stem cell research is placed in the context of the abortion debate and the unsettled and volatile nature of the discourse about embryos is based in the unfinished debate about abortion. Like slavery, such a debate is about religion, moral status, civil rights and civil duties but it is also about health care funding and

13 Stock, Gregery Silver, Lee—.

services. The debate about abortion has defined and thematized American politics since 1973, hence there was no *public* funding in first debates about fetal tissue and hence, most of the first research projects were privatized, funded by independent capital, which created labs which by federal mandate could not be located in any building or institution that used federal funds, leading to new concerns about secrecy, profits, etcetera. The need to separate controversial research from research that could be supported by a polity and their tax revenues lead to rather a further separation than some critics are now comfortable with —hence the call for more federal oversite.

The second contextual problem is that stem cell research takes place against a four decades background of unease about all things genetic. From genetic manipulation, the creation of genetically modifield foods, to issues of genetic testing and privacy, Americans, and to a larger extent Europeans, have been vocally mistrustful of the motives and aims of research genetics, and this has risen to a level of concern that has been, literally, taken to the public square, linked with globalization and colonalization. Protestors of international banking policy routinely appear in butterfly costumes, alluding to a report (never replicated) that GMO corn negatively affects butterfly reproduction.

Further, there is unease about human subjects research, as research errors have occurred at major medical centers such as The University of Pennsylvania, John Hopkins and Duke. Further mistrust is created about the ability of the marketplace to self-regulate as in the case of Enron. That several of these scandals in research (gene-therapy) and in the market (Martha Stewart) are linked to genetics heightens the context of anxiety.

VII. NORMATIVE ISSUES: THREE "BRIGHT LINES" LONG BEEN LIMITS ON RESEARCH

Social concerns have thus driven the ethical debate, and ethicists have responded with recourse to the traditional sanc-

tions suggested by bioethics' first principles: autonomy, beneficence/ non-malefience and justice. Hence, policies have been developed with strong privacy and informed consent requirements, and hence reproductive medicine has long operated with private, parental desire as both the main driver and main funding source. However, ethical boundaries were established in the 1970s to limits technologies seen then as remote. They were: a reluctance to sanction possible intervention in human inheritable genetic material; a ban on the fabrication of human embryos for research alone; and a ban on cloning (SCNT) for any purpose. HES cell inquiry challenges each of these norms, and in fact, even a close examination of several IVF methodologies reveals that here, too such "bright lines" have long been crossed. Normative oversight (civil committees, State, Federal, or scientifically based) has been called for by nearly every deliberative body who has considered the issues of the regulation of stem cell research. But in so doing, five problems will have to be decided: how will differences in strongly held religious and moral stances be expressed and defended? How will the freedom of the scientific pursuit be limited? What of the power of the ends expressed by patient advocacy groups? What will happen to violators? Who will fund such oversite? And who will be chosen to be on such committees?

VIII. IN SUMMARY

1. Arguments for proceeding: Ethical Research on Human Stem Cells can be done

Let me summarize the central arguments for actively supporting, funding and pursuing research, in stem cells.

First are the teleological (consequentialist), largely utilitarian arguments. Research on stern cells has a nearly unlimited potential for good ends. In the various diseases that affect millions world wide have as their case disadvantages cell growth or cell

death, and thus, understanding how cells grow, how they are genetically regulated, and how they develop both normally and abnormally will be key to therapy. It is this vision of future therapies and this attention to human suffering that ought to lie at the core of the medical endeavor. A correlative research end will be met by research on embryonic development. Stem cell cultures win allow an ability to test toxicity/pharmaceuticals in early embryo and in human tissues itself, a task that is dubious in animal models, and ethically unacceptable in human pregnancies. A final related telogically based argument is that such research is of itself a good end, for it allow the ability to study genetic diseases process at cellular level, using the full power of recent genomic advances in understanding causality.

Many of the diseases are the one that affect millions world wide, and would be cured-not merely treated-by the use of tissue transplants. Cardiac, cardiovascular, degeneration or trauma to the spinal or central nervous system are obvious first candidates, and that such tissue transplant has shown promise in early testing in animal models drives this argument into a central location in the debate.

Second ate the equivalency arguments: hES research is very much like other research on embryos that is already being done in universities and medical centers all over the country-IVF research in which many eggs are tested, injected with sperm, given growth factors to stimulate growth, and used as tools in teaching physicians their craft as infertility specialists. All such embryo experiments are approved by institutional research board if the work, and the embryos created therein, are destroyed at 14 days of life, just prior to the development of an individuated primitive streak. Linked to this argument is the larger one that much of early IVF research (some would say all) was a vast experiment, and that many, many embryos are created with the clear understanding that many would not survive. In fact, the protocols originally called for the implantation of up to 8 embryos in the womb, in the hopes that not all would die, thus building embryonic waste

directly into the research and currant clinical practice. If more than 3 embryos do implant, the couple is routinely offered "embryo reduction", meaning targeted and selective abortion of the "excess" embryos, in the name of saving or enhancing the lives of the remaining sibling twins.

A variant of this is based on a naturalistic premise, which permits research on blastocysts since so many are simply non-viable in the nature course of things. Thus, embryonic loss is like loss that occurs on nature, and many of the blastocysts would be lost in any case.

Third are the deotologocally (duties based) arguments. In many religions, and in secular medicine's premise, there is a duty to heal and such obligations are correlative with rights. In this argument, the limited moral status of the in vitro blastocyst determines duties to it, and the relatively larger (some say unlimited) duties to the ill and vulnerable may be primary ones. We have a duty to heal, and this is expressed in legal and social policy, and to turn away from the, possibility of healing would be an abrogation of an essential duty. Further, justice concerns may also mandate this research, for unlike whole organ transplants, tissue transplants and pharmecueticalized stem cell tissues, many be made scaleable, universalizabe, and affordable, thus allowing a widely applicable transplants. Serious issues of histocompatiability in theory block this for now, but the duty to justice would mandate a fully expressed research effort in this direction.

Making the claim for duty can be religiously motivated, or can come from other sources, such as the determinates of biology, (to protect kin, that we are dependent as neonates and need protection, that primates have a long period of parenting until adulthood. Other sources include our shared aspirational duties to improve our situation of suffering, as is argued in Christianity, or from a divine command as is posited by Judaism, or from our "experiences" as argued in american pragmatism, or of our ability to be social beings making social contracts, as Locke and Jefferson suggest. What are such duties? In other work, I have sug-

gested six;[14] 1. *Duties to make justice:* here judged by social contracts that attend to healing the most vulnerable in our society, to making therapies accessible to all; 2. *Duties to discern and judge:* here assessed by our ability to be coherent moral actors, to set limits and see differences in moral status and ability; 3. *Duties to heal the ill and save lives if we can, and care for them if we cannot:* here enacted by the inherent duty of medicine which we must extrapolate to societies, in which no self can be exempted; 4. *Duties to Guardianship:* here enacted by attention to a world unfinished and in need of (protease inhibitors, vaccines, yeasted bread, and eye glasses, etcetera). This duty of rational discourse grounds a thoughtful civil debate; 5. *Duties to be readers of text:* here meaning that interpretation and analysis of the phenomenological world is suggested by the very way knowledge is structure-imperfect, mutable, and unrevealed; 6. *Finally, duties toward solidarity:* This term, taken from European debates on genetic issues, means that activities that merely instrumentally use one another (exploitative relationships towards gamete donors, etc) are a violation of this duty.

Fourth are arguments from legal and historical precedents. Here one can turn to the example of times when a deeply divided country moved ahead on a issue of policy despite the deeply held moral opposition of many —Mennonites who opposed World War II, or Quakers who opposed the war in Vietnam offer examples of how democracies must act for the majority and how minority view must continue to be expressed, even if such dissent carries the risk of civil disobedience. America, from the time of Thoreau, has understood democracy as a serious matter of dissent as well as assent.

Finally are arguments that are political nature. Here, the arguments are as follows: If research is not funded publicly, this could drive it into private and unconsidered spheres, or could

[14] Zoloth, Laurie, "Freedoms, Duties and Limits: the Ethics of Stem Cell Research", *God and the Human Embryo*, Georgetown University Press, 2003.

limit the goods of the research to particular sectors, groups, or the needs of the market (one thinks of Viagra, instead of pediatric dieses, for example).

2. *Arguments for stopping: Stem Cell Research is immoral and ill-considered and should be banned for a time, or permanently*

The arguments against stem cell research are summarized as follows:

Deoontologiocal objections: First, stem cell research is murder of nascent humans, and is deontologically forbidden. *Arguments against stem cell research from the presidents Commission on Bioethics.* In this report, the majority argued for a moratorium on such research, with strong opposition from a significant portion of the Commission. Members agued largely deontologically, stating that the moral status of cloned embryo is nascent human life, and is thus a member of our shared humanity, and that moreover, as such, americans had a special obligation to protect vulnerable members of our social contract, the most vulnerable being entities such as this. Further, to use an embryo would be an exploitative use of human life as a tool, a serious moral wrong in addition to the moral wrong of killing. Such violations of essential dudes to care, thus create serious moral harm to society-coarsening our ideas of family union, exposing our culture to the uncertainties of asexual Further, it was argued that it was a misunderstanding of our duty to heal to think that suffering can be cured, of alleviated, especially with sacrifice of life. Here is employed that caution that there is no moral obligation to treat all disease-and it is a moral error to think we can do so, and the completary idea that it is in fact our ability to suffer, and to feel compassion for the suffering stranger that is at the base of our shared humanity. The fulcrum of this sort of deontological

argument rests on the view of suffering, frailty and limation as central to our human creatureliness and our human nature.

Second, in a teleological vein. It is argued that such research will engender a terrifying, "post-human" set of consequences—since we face a lack of moral consensus about the family and reproduction, allowing for research on this volatile and contentious issue will create political chaos. Other fear that it will *not work* and hopes for cure will be cruelly dashed, or that is *will* work and be unsafe and dangerous, or that it; *will work* and give parents powerful, morally repugnant choices such as elimination of all imperfect children, creating "designer babies," which may be, in this argument, very skillful, very beautiful, but cruel and soulless. Such choices are disturbing, and hence, and some argue, even "inherently, essentially morally repugnant" (the yuck factor is the term used by Callahan and others to describe this phenomena).

Slippery slope arguments are key to the opposition to stem cell research-a series of classic arguments that maintains that while the particular act may be marginally permissible, the road to which it leads will be a dark and downward descent. Powerful *historical precedents* I form american and german eugenics, as have been soundly exposed, document a slope of precisely this sort, in which technology was used to marginalized and eliminate the ill, the disabled, and the socially different in the years prior to the elimination of the Jews of Europe.[15] Manipulation of embryos or cloning could lead down the slope to the possibility that governments will determine which sort of life is a good one, or the cloning people will lead to two classes of human, or that human animal chimeric monsters will be created.

Third, concerns of justice are raised to argue against this research, especially feminist and environmentalist ones: It is feared that it may exploit women for their eggs, that women may be coerced, or that huge "embryo farms" will be needed to make

15 Kevles, Duster, Lombardo.

enough stem cell cultures, and that human tissue will be merely another scarce commodity to which the poor contribute, but do not have access.[16] Some raise the fear that americans already spend too much on research such as this, especially on research for the privileged elderly, and not enough on preventative health care clinics for the poor, and other fear that profit-driven private pharmaceutical companies, or illegal offshore labs will have too much control over the processes, and products of the research. Some raise the fear that such a violation of natural limits and borders is too closely akin to the errors made in the use of nature in the 19th century, and that human ecology, or a human "gene pool" may be disrupted by stem cell research. In this argument, (in part deontological and in part teleological) nature is seen as normative, morally stable and instructive.

Third are regulatory concerns: that scientists cannot be trusted to self-regulate, since a proportion of the research community believes that nature is flawed and in need of their ministrations, and this can too easily segue into their "playing God with creation", a fear raised about all genetic research. The fear that the technology will be impossible to regulate at all is behind the policy of absolute bans.

3. *From ethics to Policy in Human Stem Cell Research: Eight policy options*

Given that stem cell research in global in character,[17] with 8 of 12 sources and most lines named in the august 9th Bush Adminis-

16 Rebecca Dresser has articulated this in her section of the PCBE report.

17 Sources for the cell fine in bush compromise: National Center for Biological Sciences, Bangaglore, India (3 lines), Monash University Melbourne Australia (the National University of Singapore and ES Cell International, Pte. Ltd) (6 lines), Reliance Life Sciences, Mumbai, India (7 lines), Technion-Israel Institute of Technology, Haifa, Israel (4 lines), Goteborg University, Goteborg, Sweden (19 lines), BresaGen., Inc., Athens, GA, (and Adelaide, South Australia) (4 lines), Wisconsin Alumni Research Foundation, Madison, WI, (5 lines),

tration compromise plan for use of stem cells in research are outside of US, and given that in each place, core ideas about informed consents vary, core cultural and social meanings of IVF differ and core notions of the polity and process of oversite vary, how can one speak of coherent, reflective public policy to adjudicate between these powerful arguemments that I have noted briefly above? Leroy Walters has suggested six and I would argue for eight possible choices of policy.

First, a outright ban on all research involving stem cells. Considering this option are France, Germany, Ireland, Norway, Switzerland, Poland, Brazil, 10 states in the US (North and South Dakota, Michigan, Minnesota, Massachusetts, Pennsylvania, Maine, Rhode Island, Louisiana, Florida), and 2 states in Australia.

Second, permit use of hES cells only, and after derived from "excess" embryos from lVF clinics by others. This was the option suggested by the NIH under Clinton in 1999 and 2000, by senator Bill Frist, In July 2001 (with limit on number), by president George Bush, august 9 (with a limit on time of derivation).

Third, permit derivation from "excess" IVF embryos by stem cell researchers. This was suggested by Clinton's National Bioethics Advisory Board (NBAC), september 1999, by the European Union Group on Ethics on Science and the New Technology (november 2000), by the Advisory Group to Canadian Institutes of Health Research (march 2001), by Deutsche Forschungsgemeinschaft (may 2001), in France by 2 National Advisory Groups (january and june 2001), in Japan, by the Expert Panel on Bioethics (august 2001), in Australia by The House of Representatives' Committee on Constitutional and Legal Affairs (september 2001) by the Bioethics Advisory Board for Howard Hughes Medical Institute, by Canada, Italy, Spain, The Netherlands, 2 states in Australia and 40 states in the US.

CyThera, Inc., San Diego, CA (9 lines), University of California, San Francisco, CA (2 lines), Geron, San Mateo, CA, (2 lines).

Fourth, permit derivation and use from embryos created just for this research. This is the policy of The United Kingdom, China, Sweden, The Jones Institute, Virginia, Belgium, California, and Israel.

Fifth, permit non-reproductive cloning to create embryos for research and use of hES cells. This is an option also allowed by the United Kingdom, the California Cloning Commission, China, Belgium, Saudi Arabia, by Israel, by the Bioethics Advisory Board of the National Academy of Science and Humanities, september 9, 2001, by the US National Academy of Sciences Task Force Report: september 11, 2001.

Sixth, permit a separation compromise allowing different populations/jurisdictions do different things. In the US, this is understood as possible model for many controversial policies, often as a transitional policy ("the laboratory of the states") until concensus can be held federally (as in civil rights laws).

Seven, allow all ideas uncovered in research to be fully explored. This would include the use of animal eggs+ human DNA, parthenogenesis, etcetera, a policy followed by China.

Eight, create a limited year, or limited technique, moratorium. The PCBE has recommended such a policy and the term varies. The point of a moratorium on various parts or all of the processes from use to application would be to have more open debate in the polical arena so that all views could be fully aired. It should be noted that all of the other seven option also call for such a robust debate.

4. *Points of convergence: What can be agreed on?*

Hence we have deeply held beliefs and widely divergent policies. Can we agree on any point so convergence? I will argue that we can, and present these as candidates: first, science is a kind of free speech, but free science is a public good and hence must be honest and freely open and regulated in some way by the very

public sphere in which it aspires to be considered. Second, science must be just, with its social goods available to all, without discrimination. It must never coerce or exploit human subjects. Third, science must be prudent and safe, taking care to protect the envirment even as it alters it. Fourth, *medical* research must aim toward beneficence toward patients, whose futures and interests must be protected, Fifth, disability, aging, and illness must not be dishonored and finally, that while each human person has core human rights, such right suggest correlative duties that must be fulfilled.

5. *Points of divergence: What will we not agree on?*

There are four matters that I would argue we will not come to agree on, and we must find ways of negioating our serious differences, which are, ultimately, serious religious matters: We must come to understand that we will likely not agree on the moral status of fetuses and embryos. Nor will we agree on the definition of a family. We will not agree on what is the meaning and content of what is "repugnant" in science. We will not agree on the place of suffering in our theo-social world view.

IX. Conclusion and recommendations: creating a civic witness

Bioethics can be faulted if, after raising a chapter of questions, concerns and inqueries, it does not offer a thought recommendation of a way forward. How can we now apply ethics? How do I lead beyond a call for justice, or a call for deepening the public debate? Here are some specific recommendations. First, I would argue for the development of a range of civic responses to science research beyond the "red light/green light" approach. Research can be (rarely, I think,) prohibited, when it is abusive, deadly, or coercive (as has been done in certain human subject research);

permitted, and regulated closely by citizenship oversight, permitted with institutional oversight, and finally, research should be encougaged, funded and socially rewarded. Each project needs our assenment, rather than the projects we hear about in the press being given special scrutiny. Many, such as Alta Charo, have noted that is this largely already our practice, via the IRB/ICUC/ and NIH review process, especially in genetic research, but the mechanisms clearly need to be more fully explained to the american public so that they can be assured of research transperancy. This will mean that the public will have to come to understand, without panic, that all great research is inherently risky, given to failure, and error, and may not yield success suddenly or ever. (that is why it is called "research." Patience will have to be taught as a duty if public oversight is to be wise. Public accountability is a model for the Recomninant DNA Advisory Committee-a process begun with researchers at Asilomar, querying their own direction, and used to regulate genetic intervention. That such a limited regulatory model is in place, as opposed to the broader model used in the United Kingdom is a result of different regulatory etiologies. In the US, regulated emerged over 15 years of debate after Roe v. Wade, the unregulated growth of IVF industry (1979-1994), the commissioin of the Human Embryo Research Report, the rejection of findings and the move to state level

- UK: Warnock Report. The Human Fertilization and Embryology Authority (HFEA) 1991 present (public and private licenses and oversight)
- Public members and full open public debate
- Publish reports: standards, trials, DSMBs.
- Educational campaigns
- Oversight of all IVF procedure, use of eggs, and research protocols
- Some ongoing research vs. some moratorium
- All cloning for reproduction banned

A development of a theory of virtue for research

- What does this make of us? Thinking about our moral relationships
- How does this work shape us?
- How does one avoid evil?
- Gravitas of research
- Civil disobedience and moral dissent
- Notes toward a recommendation

May use early human embryos in research before 14 days, not frivolously, but where important new scientific knowledge can be gained or new therapies may be able to be developed, if use judiciously, in well designed research with the informed consent of the genetic providers, and full and transparent public oversight.