

## FETAL EXPERIMENTATION:

VIOLATING  
ETHICAL  
STANDARDS

The urge to conduct research for the purpose of improving the human condition or curing disease is insatiable. Researchers expend billions of dollars annually and heavily compete to announce the latest medical discovery or technological advance, or to hold out promise of a cure to rid the population of some terrible disease. But, should there be limits to such research? To what degree should human subjects be a part of experiments destined to improve the lot of humankind, especially when they are unable to give consent? In the case of fetal experimentation, to what extent are we recreating human rights abuses condemned in the past?

In the late 1980s, an entirely new strain of research was begun dependent on the abundance of abortion on demand and the technological advances of creating new human life in the laboratory. This issue of *Life Cycle* deals with two different but closely related areas of Fetal Experimentation:

### 1. FETAL TISSUE TRANSPLANTS:

The transplant of tissue from dead unborn babies who have been aborted, or live unborn babies who are about to be aborted, into individuals who have incurable conditions or diseases.

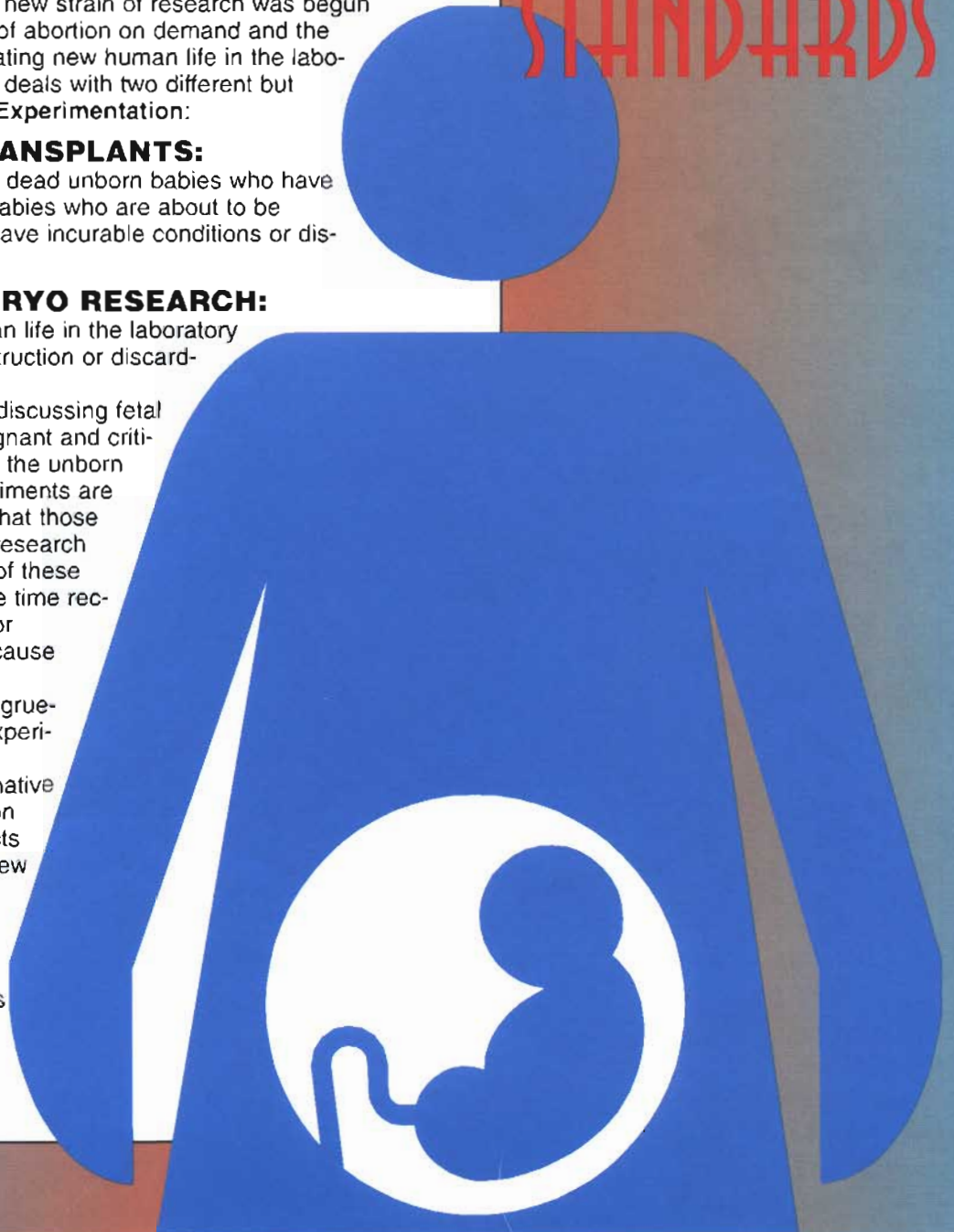
### 2. LIVE HUMAN EMBRYO RESEARCH:

The creation or use of human life in the laboratory for harmful tests involving destruction or discarding of the live human embryo.

Ethical questions abound in discussing fetal experimentation, the most poignant and critical of which is the humanity of the unborn children upon whom the experiments are conducted. It is a tragic irony that those who conduct and justify such research effectively deny the humanity of these human lives, while at the same time recognizing their superior value for research purposes, simply because they are human.

Readers will learn about the gruesome nature of some of the experiments, efforts to justify the research, the promise of alternative techniques which do not rely on the utilization of human subjects and, importantly, a personal view from a person with a progressive disease.

The stakes are high. Once we diminish the humanity of one class of human individuals to permit experimentation, all vulnerable human beings are at risk.



Among the most appalling chapters in American history are all-too-frequent examples of medical researchers willing to ignore even the most elementary canons of medical ethics when it served their purposes. Take, for instance, the infamous "Tuskegee Project." From 1932-1972, 399 poor, mostly illiterate, African-American men were told they had "bad blood." In truth they had syphilis but were not informed of their condition. Why? So that the Public Health Service could observe the untreated progression of their disease.

News of another horrible abridgement of medical ethics surfaced in December 1993, when the American public learned that from 1944 to 1974, some 4,000 human radiation experiments were conducted by or under the auspices of federal agencies. Incredibly, children with mental disabilities, sick patients, and others were routinely used as human guinea pigs.

While these examples of medical experimentation gone awry have met with universal disgust, another equally unethical human rights abuse has tragically received public acceptance: the harvesting and transplanting of brain and adrenal gland tissue of aborted babies into patients who have

debilitating illnesses, oftentimes with the help of taxpayers' dollars.

In article after article, the bodies of aborted babies have been promoted as a kind of universal donor bank. These poor victims have been hailed as a virtually limitless source of easily-obtained tissues to remedy everything from minor hearing loss to major crippling diseases such as Alzheimer's, Parkinson's disease, diabetes and, less frequently, Huntington's chorea. Alive, the unborn child is "meaningless tissue." Dead, he or she becomes a medical bonanza.

The basic utilitarian rationale for this most recent descent into barbarism is twofold. First, these babies are "dead anyway," so why not try to "get something good" from the abortion. Second, proponents contend because fetal tissue is immature, it has particular qualities which make it ideal for transplant and, therefore, theoretically more likely to work. But, in truth, all of these assumptions are either false, beside the point, or misleading.

While the most telling opposition to fetal tissue harvesting is ethical in nature, critics are also quick to highlight how, in clinical practice, the transplants simply don't work.

The main perceived "benefit" is the theoretical ability of the transplants to produce the chemical, dopamine, that is diminished in a Parkinson's patient.

Contrary to what proponents insist, there is not a single example of a Parkinson's patient with a long-term improvement whose improved condition can be attributed to a transplant of fetal brain tissue.

When there has been improvement of sorts, it has been impossible to attribute it to the

fetal tissue. There have been very few "controlled" experiments where some patients receive the fetal tissue transplant while others with the same condition do not, and both are tracked to compare results. Without this point of comparison, and validation by other researchers, there is no way to prove the fetal tissue had anything to do with signs of improvement.

But even more devastating for proponents of fetal tissue transplants is that once one understands the many things that must go right for a transplant to have any chance of working, it is obvious that chances of success are infinitesimally small. (See chart on page 4.)

The ethical case against fetal tissue transplants is more basic:

1. These unborn children should not have been killed in the first place, and should not be further exploited by the scavenging of their body parts.

2. A hand-in-glove relationship between abortion facilities and researchers utilizing the aborted infants' tissues is necessary, lending greater legitimacy to the abortion industry by integrating it into the medical research enterprise.

3. Researchers and recipients of fetal tissue "treatments" will be required to set aside moral objections to abortion, as they become dependent on abortion for medical benefits.

4. Commercialization will result if a market is created for selling fetal tissues.

5. If transplants should become successful in treating diseases which affect many Americans, "supply and demand" will inevitably create a clamor for more abortions to provide a constant "supply" of fresh tissue.

6. By creating a new "benefit" from abortion, this research will be used to tell a woman that abortion is not only good for her, but will "help humanity." This could be used by husbands, boyfriends, parents, or others to pressure a woman to abort.

7. Some women have already expressed interest in becoming pregnant for the sole purpose of aborting and donating fetal tissue to a relative.

Proponents of fetal tissue transplants have argued that by instituting safeguards, we can prevent abuses. But as federal advisory panels dis-



# Medical Ethics and Transplants: Are They Compatible?

By Dave Andrusko

cussed fetal transplants in the 1980s, it became clear that initial minimal safeguards were either unenforceable or highly unlikely to survive.

For instance, debate was at its most ferocious in 1988 during hearings conducted by the Human Tissue Fetal Transplant Research Panel. In approving federal funding of fetal tissue transplants, a majority of the panel insisted that would not change how/whether/when abortions would be performed. For instance, they said women would not change the time in pregnancy when they aborted in order to secure the "best" tissue.<sup>1</sup> (Transplants for Parkinson's patients come from unborn children roughly 8-12 weeks old; for diabetes, the age range of babies is from mid-to-late second trimester.) In addition, they assured skeptics, it was possible both to erect a "wall of separation" between the abortion clinic and the research dependent on fetal remains, and to guarantee that women would neither be pressured into aborting a child they would otherwise bring to term, nor induced into conceiving a child for the purpose of aborting the child.

But, in reality, there is no way to patrol what clinic personnel and medical researchers actually do. The abortion industry is already the largest unregulated industry in the U.S. Moreover, accounts have appeared in the popular press, illustrating how closely the parties work together.<sup>2</sup>

Some supporters have gone so far as to admit that if using recently aborted unborn babies did not work, they would take live unborn babies. Prof. Mary B. Mahowald of Case Western Reserve University has written that it is "morally defensible" to remove organs or tissues from "non-viable" fetuses (in the first six months of development in the womb) while they are still alive, "if dead fetuses are not available or are not conducive to successful transplants."<sup>3</sup>

Mahowald acknowledged "added concerns" because of the children's "possible sensitivity to pain," but said "this concern may be satisfactorily addressed on a practical level by using anesthesia."<sup>4</sup>

Transplantation of tissues and organs from aborted babies to cure

disease is not the only suggested use. Some British and American doctors have even proposed transplanting the ovaries of aborted female babies into infertile women as a cure for infertility.<sup>5</sup>

If we accept the rationale that we may exploit these babies for our benefit because they are "going to die anyway," that logic is sure to open the door to assaulting other individuals—such as patients with disabilities—for the "benefit" of the more "valued" members of society. The debate over reaping the organs of babies born with anencephaly, a very severe brain deficiency, is highly instructive on this point. Initially, it was argued that their organs could be taken if they were brain dead. Then it became obvious that by the time these babies are genuinely brain dead, their organs are no longer useful for transplants. Those who had previously vowed adherence to accepted brain-death criteria began to lobby for an "exception" for babies with anencephaly. Why? Because their lives were not "meaningful" and because, lacking an upper brain, anencephalic babies could not, we were told, be said to qualify as a "person" whose interests have to be recognized.

The American Medical Association's Council on Ethical and Judicial Affairs came out in favor of taking the organs of these still-alive babies in June of 1994.<sup>6</sup> It reiterated its position and explained its rationale in the May 24, 1995, edition of the *Journal of the American Medical Association*.<sup>7</sup> George Annas, an ethicist at Boston College, said the council was advancing "a horrific and horrendous idea." These children "are real live human beings," he told the *New York Times*. "They are extraordinarily handicapped, but they are live human beings."<sup>8</sup> The council's position, Annas said, blurs the line between life and death. In late 1995, the AMA, under fire from its own governing body and bioethicists such as Annas, reversed its stand and opposed killing and organ-harvesting of babies with anencephaly.

It takes no imagination to see that taking the organs of many other classes of cognitively-impaired people, such as babies born with severe men-

tal disabilities or people diagnosed as being in a "persistent vegetative state," would be a natural progression should organ removal from infants with anencephaly become accepted practice.

The price we are paying for this entire assault on the sanctity of life ought to be unacceptable to any civilized nation. Our children are at risk of becoming nothing more than consumer goods. Inexorably, other mentally and physically powerless people will be targets in the relentless search for new sources of "spare" parts.

Primo Levi discovered in Auschwitz that there is a fate worse than death, and that is to lose our respect for our own humanity. Once we accept the idea that the end justifies the means in medicine—or anywhere else—we run the risk of undermining the basic values that make civilization possible.

## NOTES

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# FETAL TISSUE TRANSPLANTS

## DEFINITION:

Taking tissue from organs of an aborted infant and transplanting it into the body of another individual as a treatment for a condition or disease. If intact, whole organs of an aborted infant are also transplanted.

## TECHNIQUES FOR TRANSPLANTING FETAL TISSUE

A brain transplant occurs by either opening up the brain and physically placing the cells in the targeted sections of the brain of the recipient, or by boring a small hole in the skull and injecting the cells into the targeted area using a precise mapping technique for correct placement. For a disease such as juvenile diabetes, cells are injected directly into the abdomen.

### ETHICAL CONCERNS:

1. Sensitivity to pain for the living unborn child.
2. Pressure on women by husbands or boyfriends to abort for supposed "humanitarian" reasons.
3. Women becoming pregnant for the sole purpose of creating "tissue" to be used for an ailing relative or even themselves.
4. Abortions delayed to later in pregnancy to create optimum gestation for certain tissue.
5. Increased number of abortions and creating an incentive to keep abortion legal because of increased demand for more fetal tissue.
6. Forcing taxpayers to fund ethically questionable treatments of doubtful outcome through government funds.
7. Question of proper consent for the unborn child since the mother has already agreed to destroy the child.
8. Abortionists and researchers working hand in hand to create/harvest fetal tissue, creating a conflict of interest.
9. Commercialization or sale of tissue, particularly impacting on minority women, who will be pressured to conceive

and abort for financial gain.

10. Ignoring requirements that born babies be brain dead before fetal tissue is removed.

11. Expanding logic of using tissue of aborted children to include harvesting from other "non-sentient" (unaware) individuals who "are going to die anyway."

12. Justification of the concept that non-consenting, non-beneficial research is acceptable if the human being is going to die anyway.

### TECHNOLOGICAL LIMITATIONS:

1. Determining how much tissue to use for each transplant because very few fetal cells survive.
2. Survival of fetal cells from the force of suction in a suction abortion and subsequent handling.
3. Survival of fetal cells when transferred from the fetal brain.
4. Survival of fetal cells from preservatives and freezing techniques.
5. Survival of fetal cells from injection deep into the patient's brain.
6. Survival of fetal cells from the trauma of the needle stab, inevitable hemorrhage, and other tissue damage.
7. Survival of the fetal cells when confronting the host's immune system and possible rejection of the foreign tissue.
8. Survival of the fetal cells in attempting to establish enduring and accurate links with the appropriate cells in the relevant parts of the recipient's brain.
9. Determining where the transplant material should be placed.

## Fetal Tissue Transplants: Failure or Success?

by Paul Ranalli, M.D.

On January 22, 1993, newly inaugurated President Bill Clinton signed an executive order lifting the Bush administration ban on the use of tax dollars to transplant fetal tissue from aborted babies. Claiming that such fetal brain and adrenal tissue might provide a miracle cure for a number of neurological diseases, Clinton overrode both the ethical objections of opponents and the considerable medical evidence that fetal transplants are unlikely ever to work.

In the area of fetal brain transplantation for Parkinson's disease, there have been dramatic claims but precious little scientific evidence of effectiveness.

Unfortunately, millions of Americans, including the nearly one million with Parkinson's disease, may be impressionable — or naively hopeful — enough to believe fetal transplants are an established treatment for Parkinson's disease. An ongoing wave of positive media reports have suggested there is new and exciting scientific evidence of the increasing success of fetal transplants for Parkinson's disease.

Such evidence has not surfaced. The silence, in fact, is deafening. Not one clinical study has been published since the original cluster of three reports from Sweden, the University of Colorado, and Yale University (totalling just 13 patients) was pub-

## TECHNIQUES FOR OBTAINING FETAL TISSUE:

1. Sifting through the remains of an aborted unborn child to locate specific tissue from the liver, pancreas, or brain.
2. Using a suction abortion method with ultrasound that produces an intact aborted infant in order to obtain tissue recognizable as coming from a particular organ (as best as can be determined from researchers, who are reluctant to reveal technical detail about the abortion and tissue extraction.)



## ALTERNATIVE TREATMENTS: PARKINSON'S TREATMENTS

1. Self-repair of the brain by ingesting a substance called Gm1 ganglioside.
2. Bathing stem cells, which are precursors to mature cells, in a potent protein growth factor to encourage growth of the cells, then used to stimulate self-repair of the brain.
3. Drugs to replace loss of dopamine, a neuro-transmitter, which is depleted in Parkinson's patients.
4. Discovery of new ways to produce large quantities of dopamine, and graft the source into a patient's brain to control Parkinson's symptoms.
5. Drugs which interact directly with dopamine receptors in the brain.
6. Drugs to stabilize diseased brain cells and limit further deterioration.
7. Drugs to encourage brain tissue regeneration.
8. Surgical lesions (cuts) into deep brain structures which are abnormally overactive in Parkinson's disease.

## OTHER TREATMENTS

1. Lesion (cut) into the brain to reduce impulses which interfere with a patient's muscle function.
2. Chronic stimulation from a type of small pacemaker placed deep in the brain.
3. Using combinations of "trophic factors" or natural substances to slow or reverse degenerative diseases.
4. Isolating monkey "stem cells," which are similar to humans, to evolve into body cells to be transferred to humans.
5. Preserving or restoring nerve cells in the brain (with application to Parkinson's) and in the spinal cord (with application to Lou Gehrig's disease) through a protein called "glial-cell-line-derived neurotrophic factor" (GDNF), currently showing promise when used on animals.

lished in a November 1992 issue of the *New England Journal of Medicine*. Although heralded as a "breakthrough," upon closer inspection these studies were remarkably disappointing.

Only one of 13 subjects from several studies was a true Parkinson's disease patient who may have shown modest improvement; even he still required medication for his condition. Ten other subjects were a collection of treatment failures, inadequate follow-up, complications, and one death. Two subjects from Sweden who seemed to be doing well did not have Parkinson's disease at all—they suffered from a chemical brain poisoning condition (MPTP

toxicity) that mimics Parkinson's disease, but does not have the same relentlessly progressive course.

In the *Canadian Medical Association Journal* in November 1994, Dr. Alan Fine, Ph.D., Department of Physiology and Biophysics, Dalhousie University, Halifax, Nova Scotia, Canada, one of the foremost proponents of fetal tissue research, summarized the experience of over 140 patients with Parkinson's disease around the world who have received fetal brain tissue transplants. He stated: "Improvement was reported in most cases. However, inadequate documentation and lack of standardization make it difficult to evaluate most of these claims,

and even well-documented reports have been criticized." This admission sounds remarkably like the criticisms first leveled against this type of work in its initial stages.

In contrast, many new technologies documented in the chart above show far greater promise than fetal tissue transplants in benefiting patients with progressive diseases.

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# LIVE HUMAN EMBRYO EXPERIMENTATION

## DEFINITION:

Creating or using live human embryos, not to benefit the individual embryo but to gain knowledge that may be helpful to other humans in the future. The live human embryo is generally destroyed in the experiment or discarded once the experimental purpose is accomplished.



## EXPERIMENTS USING LIVE HUMAN EMBRYOS

Recommended for federal funding by advisors to the National Institutes of Health:

1. Using unwanted or "spare" embryos from *in vitro* fertilization programs to test the effect of different cultures and other influences on developing embryos.
2. Specially creating "research embryos" to observe the process of fertilization, followed by discarding of the embryos.
3. Observation of embryonic development up to the appearance of the "primitive streak" that will form the basis for the spinal cord (18th to 20th day of development in the laboratory), followed by discarding of the embryo.
4. Use of "parthenogenesis" (doubling the genetic makeup of an ovum without fertilization by sperm) to create embryo-like organisms for research and destruction.
5. Obtaining eggs from women in infertility treatment programs, and from dead women and children with consent of next of kin, to create embryos for research and destruction.
6. Refining "preimplantation genetic diagnosis" to test human embryos for genetic defects, followed by discarding of embryos found to have any genetic defects.
7. Developing human embryos in the laboratory to the point where tissue differentiation begins, and dissecting the live embryos to obtain "stem cells" for research and transplantation.
8. "Cloning" human embryos by transplanting the nucleus from a human cell into an embryo whose nucleus has been removed; such duplicate embryos are to be experimented on and then destroyed.

## Recommended for "additional review" before receiving federal funding:

1. Observation of human embryo development from the appearance of the primitive streak up to the beginning of "neural tube closure," when the early spinal cord takes final form (4th week of development); followed by discarding of the embryo.
2. Artificial "twinning" of embryos by "blastomere separation" or "blastocyst splitting" (separating one cell from a multicelled early embryo to form a new embryo with the same genetic code); followed by discarding of the embryos.
3. "Cloning" by nuclear transplantation to correct a genetic defect, with the cloned embryo implanted in the uterus for live birth.
4. Specially creating "research embryos" to be grown and dissected into useful "stem cells" for research and transplantation.
5. Fertilizing eggs harvested from the ovaries of aborted fetuses, to create embryos for research and destruction.

## Hopes of the ill should not rely on abortion-dependent research



by  
**Christopher Currie**

I have suffered from juvenile-onset diabetes for nearly two decades, and I have been insulin dependent for

almost 18 years. I follow a daily treatment regimen of blood glucose monitoring, multiple insulin injec-

tions and regulations of diet, exercise and other activities. Despite my relatively good diabetes control, as time goes on, I become ever more vulnerable to the specter of severe health complications and even death.

Even now, I struggle with the onset of several dangerous conditions, including background retinopathy, which leads to blindness; renal protein leakage, which may hasten kidney failure; and loss of blood circulation and nerve response in my extremities, which eventually may result in loss of life.

I talk frankly about my condition so that people realize that the issue of ethical or non-ethical fetal tissue research is not just an academic matter to me, but is bound up with my deepest fears, hopes, and expecta-

tions. My perspective is personal, of one who ultimately stands to gain or lose by the acceptance of this controversial research on aborted children. It is cruel to have one's anxieties and desperate hopes cynically manipulated for political ends, and to be victimized by the well-intentioned but misguided "compassion" of others.

I have already experienced the fruits of legitimate diabetes research in many ways, for instance, the development of genetically engineered human insulins and the advent of home, blood-glucose monitoring systems. Current research offers new and exciting possibilities, including the transplantation of encapsulated insulin cells from animals and the modification of the



## Deemed by NIH advisors as “unacceptable for federal funding” at the present time:

1. Implanting artificially “twinned” embryos in the uterus to be brought to live birth.
2. Implanting embryos cloned by nuclear transplantation in the uterus for live birth, to duplicate a genome or create more embryos with the same genetic code.
3. Experimenting on embryos in the laboratory beyond the onset of closure of the neural tube or the fourth week of gestation.
4. Implanting in the uterus any embryos produced from eggs taken from aborted fetuses, or eggs activated by parthenogenesis.
5. Using preimplantation genetic diagnosis to discard embryos of an unwanted sex (or with a sex-linked genetic disorder.)
6. Creating human-animal hybrids or “chimeras,” except that cross-species fertilization may be done to test the viability of human sperm (the “hamster test”).
7. Implanting human embryos into animals for gestation.
8. Using human embryos to attempt extrauterine or abdominal pregnancy (e.g. “male” pregnancy).

## ETHICAL CONCERNS:

1. Showing disregard for human life, by destroying and discarding such life at an early stage of development.
2. Treating human subjects as merely a means to an end, as when subjects are created solely for research purposes and then destroyed.
3. The prospect that the rationale now used to experiment on embryos could be extended to other “non-sentient” human beings—anecephalic infants, comatose patients, or elderly persons with dementia.
4. The potential for inflicting pain on living human embryos as experiments are pushed later in human development.
5. Forcing taxpayers to become involved in ethically questionable or destructive experiments by providing government funding for them.
6. The impossibility of obtaining “informed consent” when harvesting eggs and ovaries from anencephalic infants, dead children or women, and others unable to speak for themselves.
7. Exploitation of poor and minority women to provide eggs and embryos for research and destruction.
8. The possible harm, including increased cancer risk, which super-ovulation and egg retrieval procedures pose to women donating eggs for creation of “research embryos.”
9. Confusion and distortion of concepts of family and parenthood when embryos are created without fertilization (by cloning, parthenogenesis, etc.) or created from eggs supplied by dead infants or unborn children.
10. Blurring the concept of humanity by cross-fertilizing humans with animals.
11. The dangers of commercializing human life by creating a “market” for human eggs and embryos.

body’s own skin cells to produce and regulate insulin.

Now millions of diabetics like me are being wrongly told that our best hope for a cure lies in unethical abortion-dependent fetal tissue research. Yet this unproven treatment, even if it did work, would at best benefit a few thousand patients a year, who would then spend the rest of their lives wrestling with the knowledge that a little person had to forfeit his or her life to improve the quality of theirs.

I, for one, resent my hopes being trampled upon in this manner. Moreover, even though I would never consent to ghoulish fetal tissue therapy, I adamantly protest the idea of redirecting scarce federal research money away from promising and

ethical research projects that could benefit many like me, and sinking these dollars into the black hole of unethical, abortion-dependent, fetal experimentation, where it probably would benefit no one, least of all the tissue “donors.”

More importantly, we disease victims need to speak for ourselves and to be regarded as full human persons by others. Disease victims are not merely bio-machines whose well-being is solely a factor of their physical health. We have minds and souls like everyone else, and possess consciences that are as fully sensitive as those of healthy people.

Proponents of unethical fetal research say that only people who have no stake in the outcome of the research oppose it. In fact, it is the

disease victim himself who has to live with his conscience as he lives off of the remains of someone else’s life. I wouldn’t wish that awful fate on anyone; people should listen to disease victims when we say we don’t want to be forced to choose between physical suffering and mental and spiritual agony. Disease victims want ethical therapies that will restore health without violence to us or other innocent victims.

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# The Human Embryo Research Panel: Creating Life to Destroy It

by Richard Doerflinger

In a meeting room at the Bethesda Marriott near National Institutes of Health (NIH) headquarters, 19 individuals quietly made history February 2 and 3, 1994. As the Human Embryo Research Panel, they convened the first NIH hearings in 15 years on the issue of federal funding for live embryo experiments. They made it clear that if they have their way, American taxpayers will have to pay for those experiments for the first time in history.

Since the mid-1970s, government regulations have banned federally-funded experiments on live unborn children unless the experiment can help that particular child or poses no significant risk to him or her.

But these regulations only protect the child beginning with implantation in the womb—leaving a huge loophole in efforts to protect a human embryo produced in a laboratory.<sup>1</sup> That gap in the law can be exploited to allow some of the most bizarre and controversial experiments ever done in the name of scientific progress.

Panel Chairman Steven Muller of Johns Hopkins University was careful to remind the Panel members of their mandate: to decide *which* embryo experiments to recommend for funding, *not* to discuss whether such experiments should be funded at all.

The panelists also discussed some kind of development time limit beyond which destructive experiments would not be allowed. Some countries allow such experiments only until 14 days after fertilization, and some policy bodies use the word “pre-embryo” to describe embryos before that 14th day.<sup>2</sup>

Whatever the cutoff date, the idea was that once the date is reached, any embryos left alive would not be protected but would be discarded before they could develop further. And because the cutoff line is arbitrary, it could be moved up whenever “important” experiments require use of a later developmental stage. The panel agreed in principle that **no** unborn child before viability has any “rights” or “interests” at all.

At its second meeting the panel heard several enthusiastic presentations on the scientific “progress” that destructive experiments on human embryos would provide. Even before these presentations were over, Muller was pressing the other panelists to discuss the “14-day” time limit mentioned during the panel’s first meeting.

The scientists on the panel **all** opposed this limit. Others cited the “scientific benefits” of studying embryos into later stages. Panelist Patricia Donahoe said that “it would be a shame to limit ourselves” to 14 days. But other panelists said some limit might be needed as “a political compromise” in a society where some people might be “upset” about the idea of embryo research.<sup>3</sup>

The panel concluded that an initial time limit would help the public get used to the idea of experimenting on embryos; then public “sensitivities” could be assessed before moving further. In other words, if you raise the bath water one degree at a time, you can boil Americans’ “sensitivities” down to nothing and they may not notice. Any “limit” initially set by this panel would not be a barrier but a mere “speed bump” on the road to a brave new world of untrammelled experimentation.



An opposing viewpoint was presented in public comment by Diane Irving, professor of philosophy, DeSales School of Theology, Washington, D.C., and former NIH research biochemist. She referred the panelists to her 400-page dissertation, which analyzes 23 articles claiming that human personhood appears at some point after conception. When she began the project she expected to end up supporting the idea that a human individual does not exist until 14 days after conception.

"To my own amazement," she said, "I discovered that in all 23 arguments, the science was incorrect, the philosophy was historically incorrect or indefensible and none of the conclusions followed logically from their premises." She pointed out that "fake human embryology," based on invalid analogies to amphibian development, has formed the basis for such theories about the human embryo.

Irving insisted that the need for medical progress cannot override the need to respect human beings. "You can't use vulnerable human beings for experimental research for the greater good of society simply because they're easy to have."<sup>4</sup>

Commenting on this need to "respect" human embryos, panel consultant Charles McCarthy later proposed that "using or involving an embryo in research may in and of itself be a mark of respect," even if it involves destroying and discarding the embryo.<sup>5</sup> Panelist Brigid Hogan agreed: "Perhaps the way you can show the most respect to an embryo is to do the very best possible research with it from a scientific point of view."<sup>6</sup> The honor of being destroyed for particularly interesting knowledge was, of course, not the kind of "respect" that Irving meant.

At its third meeting, the panel focused on several topics: the "moral status" (or lack thereof) of the human embryo, and the prospects for specially creating embryos as guinea pigs for harmful experiments; particular experiments that NIH might classify as acceptable or unacceptable; and the advantages and disadvantages of harvesting eggs from live volunteers, brain-dead women, or aborted female fetuses to create research embryos.

Panelist Ronald Green argued that the case in favor of a human being's value or moral "protectability" becomes "more and more compelling" as later stages of development are reached. In a published article cited in the panel's final report, he argues that "protectability" or personhood declines again later in life, with disability and old age, and may never be achieved by some people with serious mental disabilities. The panel ultimately endorsed Green's sliding-scale theory of human worth, in effect undermining the "personhood" of some people already born.<sup>7</sup>

Green suggested that the embryo takes on more value when the so-called "primitive streak" appears and forms an axis for orienting further development (around the 14th day of development in the womb, or the 18th to 20th day in a laboratory setting). Even after that point harmful experiments could be done if the knowledge to be gained is important enough. Panelist Brigid Hogan agreed with this approach: "We want to leave it [the opportunity for experiments at later stages] open in the future," she said.<sup>8</sup>

Green specified that embryos should "always be handled with respect." This guideline came in for some bemused

comment, since these embryos will be subjected to toxic chemicals and other harmful influences and then incinerated. Green conceded that the meaning of "respect" in this context is "a very difficult question" when you are destroying and discarding the beings you claim to respect.

The panel also decided to favor creating embryos solely for purposes of destructive research. But it was unsure where to obtain the unfertilized eggs from which to create such "research embryos."

Patricia King, one of two African-American women on the panel, was concerned that if there is financial compensation for donating eggs, low-income women would be pressured by financial need to participate. Finally she pointed out a racial aspect of this research. At present, couples "buy" eggs and embryos for their own reproductive purposes, and "nobody goes looking for a poor or minority gamete donor." But if researchers create a market for eggs and embryos destined for lethal experiments, "You vastly enlarge the potential of exploitation and coercive practices; fiscally desperate African-American women may be sought out, since no one will care what skin color these embryos would have had when born."<sup>9</sup>

It was hard to deny that her scenario is plausible. One of the most controversial fetal experiments ever funded by the NIH was performed solely on low-income African-American and Hispanic women in south central Los Angeles in 1979.<sup>10</sup>

At its fourth meeting, the panel decided that human embryos in the laboratory can be subjected to destructive experiments that would never be allowed on embryos residing in their mothers' wombs. They would not support experiments posing a serious risk of harm—but "risk" would mean the "risk of a child *being born* with some kind of deleterious [damaged] condition." The whole concept of "harm" would be irrelevant as long as one makes sure a damaged embryo does not survive to term. As panelist Alta Charo candidly observed, "We're already ready to destroy them, so to talk about harm seems a little bit disingenuous."

Procedures like "preimplantation genetic diagnosis" (testing embryonic cells for signs of abnormality) were favored because they facilitate what Hogan called "the discard of genetically abnormal embryos." If an embryo *initially* intended for transfer to the womb were found to have a defect, some panelists saw a moral *obligation* to destroy it.<sup>11</sup>

The panel then turned to the deliberate creation of embryos solely for research purposes, with no intention ever of transferring any of them to the womb. No one worried about "harm" to these embryos, because all of them would be intended for destruction from the outset.

Here the issue of "supply" reared its head. Chairman Muller said the panel probably needn't worry that "there's going to be a terrible need for hundreds or maybe thousands of embryos," but the scientists on the panel quickly corrected him. According to Dr. Mary Martin, "you probably need hundreds of embryos" for a **single experiment** to get a reliable result.<sup>12</sup>

The panelists favored using eggs from dead women to create embryos for destructive experiments, with nothing

more than the usual consent from "next of kin." They further discussed harvesting dead children's ovaries with the consent of their parents. Panelist Professor Tauer objected to the use of dead children, but was quickly corrected by panelist Dr. Ryan, who said that excluding children would "condemn" them to being "unable" to participate in and "benefit" from embryo research.<sup>13</sup>

Almost the only experiments the panel seemed prepared to prohibit were those which may lead to a live birth. It saw no problem with using federal funds to create, manipulate, and throw away hundreds or thousands of human embryos a year.

Though besieged by thousands of angry letters from critics, the panel used its fifth and last scheduled meeting in June of 1994 to recommend federal funding of many experiments that are illegal in several states and other industrialized nations. It then released its final report in September, and presented its recommendations in December of 1994 to the NIH director and his personal advisory committee. In defending the panel's ethical approach to this committee, Green noted that "It's obvious that Americans hold very different views" on the moral status of the human embryo. "It is not our role," he said "to decide which of these views is correct." He then proceeded as though one extreme view is correct, by claiming that a *failure* to do lethal experiments on embryos will inflict unacceptable "harms" on children and adults who could have benefited from the results.<sup>14</sup>

Green advised the NIH to approve the panel's entire report, but implement it in a "targeted" way, at each stage approving whatever public sentiment will tolerate. Dr. Ralph Snyderman of Duke University agreed: The NIH could experiment on "spare" embryos from infertility programs first, then "educate the public over time to go beyond that." This open-ended "incremental" approach ultimately prevailed.

Responding to the Advisory Committee's action on December 2, 1994, President Bill Clinton declared, "I do not believe that

federal funds should be used to support the creation of human embryos for research purposes, and I have directed that NIH not allocate any resources for such research." But as the panel and Advisory Committee already knew, this disallowed only a few current grant proposals — Muller said it affects "just one little part of our recommendations."

Clinton's decision to fund destructive experiments on "spare" embryos, while barring the use of federal funds to create "research" embryos, established a strange new policy: Government funds may not be used to **create** human embryos but only to **destroy** them. The inconsistency of his approach helped ensure that debate on this issue will intensify in the future.

### Notes

1. Since 1975, federal regulations on fetal research have defined a "fetus" as "the product of conception from the time of implantation..." (45 CFR Sect. 46.203(c)).
2. Transcript, National Institutes of Health Human Embryo Research Panel (henceforth "T"), 2/3/94, pp.8, 59-60.
3. T, 3/13/94, pp.82-4; also see 4/11/94, p.23.
4. T, 3/14/94, pp.88-92.
5. T, 3/14/94, p. 132.
6. T, 3/14/94, p.138.
7. See R. Green, "Toward a Copernican Revolution in our thinking about life's beginning and life's end," *66 Soundings* (Summer 1983), pp. 152-173. Green's article was cited approvingly by the Panel as a "philosophical statement" of its own position: Final Report of the Human Embryo Research Panel, p. 49, n.13.
8. T, 4/12/94, p.3.
9. T, 4/12/94, pp.32-3.
10. The project is described by its director, Dr. Ezra Davidson, in National Institutes of Health, "Report of the Human Fetal Tissue Transplantation Research Panel," Vol. II (December, 1988), pp. D82-9.
11. T, 5/3/94, pp. 46-8.
12. T, 5/3/94, pp. 35-6.
13. T, 5/4/94, p. 64.
14. Transcript, "National Institutes of Health: 69th Meeting of the Advisory Committee to the Director," 12/1/94, pp.68-9.

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# HUMAN EMBRYOS:



## RESEARCH SOURCES?

by Joseph J. Piccione, J.D.

On December 2, 1994 President Bill Clinton, approved elements of a report from the National Institutes of Health, regarding the recommendation of the NIH Human Embryo Research Panel to initiate federal funding for experiments on developing human life at the embryonic stage. These experiments are not therapeutic, that is, to aid these youngest human lives. Strangest of all, these human embryos will not survive the research activities. They will merely be "used" as sources for research data.

Clinton's decision to approve this type of research was unparalleled. History was made both with respect to research funding, but more importantly, regarding the ethical standard used to arrive at this decision. Scientists who urged the acceptance of this panel report are elated because they claim they will gain new access to information on the beginning stages of human life...in other words, it will be good for research. But other scientists opposed this measure and were dismayed at the president's approval because it represented a

betrayal of a fundamental respect for human life in research and experimentation.

The real historical interest in the president's approval is the further erosion of ethics in research science; a tearing down of fundamental protection of human subjects and exposing them to unjust treatment. Because this high standard of ethics was established only after previous horrors shocked the world, its loss now is all the more tragic.

### **Ethics in Scientific Research**

All human professions and activities are oriented toward goals, and have values and norms for the conduct of activities to attain the goal or outcome. These values and norms, with the goal in sight, form the profession and the persons in it. They are the "ethics" of a profession. Ethics is derived from the Greek word "ethos" which is translated "custom" or "conduct." In our use of "ethics" we refer to decisionmaking that is in accord with the criteria of a purposeful activity or profession.

Ethics, then, is a primary concern in a profession. Ethical reflection on an activity is for the sake of attaining a good goal in a good way. A good end or goal does not justify an evil or unethical means to attain it. Within ethics, consideration of our relations with others are evaluated by the standard of justice, which is a virtue by which persons are given that which is due them.

In our time, science has been given great respect in our culture due to the accomplishments it has achieved. Many scientific breakthroughs have greatly benefited human life. What makes scientific and medical advances possible is the knowledge that comes from research. But according to the ethical and social norms of our society, research data and knowledge must be attained in a sound manner. Scientific knowledge can be a good to serve human life, but it is not an absolute good that exempts research from the requirements of ethics.

At issue in the NIH proposal is whether human embryos may be reserved for research purposes, with

their lives terminated during or after the project activity. Federal funding for this research was approved by Clinton although he did not permit federal funding for the creation of human embryos for the research.

The scope of the current approved activity is of ethical concern because it rejects the fundamental protection merited by innocent human life. A reflection of the value of protecting human life is seen in this basic ethical principle of research on human subjects—namely, that the subjects benefit, or are at least not harmed, by the study. (Risk of harm in research requires free and informed consent of the participant, which is impossible in the case of the pre-born, who have special legal protection in the course of research activities.) This fundamental value and ethical norm was wholly rejected by the NIH and President Clinton.

Many in the medical and research community reacted against the direction the NIH panel had taken from its start. Robert J. White, M.D., Ph.D., Director of Neurosurgery and Brain Research Laboratory, MetroHealth Medical Center, Cleveland, Ohio, stated in an interview: "If one believes that human existence begins at the moment of fertilization, then obviously all research conducted on embryos, regardless of age or maturation, represents a totally unacceptable abrogation of their personal rights." (*American Medical News*, June 20, 1994)

Micheline Mathews-Roth, M.D., Associate Professor of Medicine, Harvard Medical School, also stated opposition to human embryo research and described the application of the virtue of justice in medical practice and research: "From the zygote stage on, an organism remains a member of its parents' biological species. Thus, if we are bound by basic medical ethics not to deliberately harm a member of our own human species, this rule should apply to all humans, regardless of age." (Op.cit.)

Consequently, there is a fundamental principle at issue: should developing human life be respected as inherently sacred, or may human life simply be reduced to a means of gaining

scientific knowledge? Put in an even more straightforward manner: is a living human distinct from any other lab specimen?

### **Medical and Research Ethics in the Twentieth Century**

Concern about ethics issues in medical research has been prominent at key points in the 20th century. The most appalling evidence of a lack of respect for human persons is evidenced by the ghastly experiments performed by Nazi doctors in Germany during World War II. In the name of medical advances, these physicians routinely caused the death of countless Jewish, Polish, Russian and Gypsy prisoners in experiments involving intended infection, freezing, or simulated high altitude conditions.

In the Nuremberg trials following World War II, a horrified world learned of the extent of these experiments, provoking international dedication to ethics standards in the medical profession, and human rights declarations by the United Nations Organization.

Earlier this century, the U.S. Public Health Service conducted unethical research on poor, rural, African-American men who had syphilis. In what came to be known as the Tuskegee experiments, scientists wanted to observe the natural progression of the disease and its eventual fatal result. However, during these research years, penicillin was found to be effective against the disease, but, shockingly, the research subjects, uneducated rural men, were never told of this. Instead, they were left to die—untreated—because the study was designed to gather the data of their sickness and death, not to aid them in returning to health. This was unjust for two reasons: first, these men never gave their consent to continue in the research project under this condition; second, the project did not provide a known beneficial treatment to the research subjects.

Eventual recognition that this research program was planned and operated by a U.S. government agency resulted in federal legislation protecting human research subjects

(45CFR 46.201ff). During the early 1970s, additional research activities in which consent was absent came to light, notably regarding experimentation on babies who survived late-term abortions, deliberate infection of elderly residents in a Baltimore geriatric facility, and infection of children with mental disabilities in a residential facility on Long Island.

Our current ethical research standards are high, but have come at a costly price paid by vulnerable persons. We should be ashamed if we would now lower our ethical standards, by drawing a line around living human embryos, excluding them from humanity for the sake of data collection. In its noble search for knowledge applied to the good of human beings, scientific research must be ethical. Compromising ethics will cause an immoral flaw in the research, and future generations will chastise us for our moral lapse.

Mathews-Roth reminds us of the need to maintain high ethical standards: "To deny respect to certain members of the human species because of age or physical condition is clearly discriminatory. It is also relaxing the guard which must be kept up at all times, to prevent our society from abusing our own kind, as was done in the Nazi experiments on concentration camp prisoners, the Tuskegee experiments, and the exposure of unknowing civilians to radioactivity."

Live human embryo research presents a challenge to civilization and its standards. To be consistent with the inherent dignity of all human beings, the recognition of

humanity should lead us to prohibit such research, much less provide federal funding for it.

Deviation from the standard and philosophy of respect for all human lives demonstrates acceptance of a utilitarian philosophy. Utilitarianism seeks to promote the good and happiness of the many, but is willing to sacrifice a voiceless minority of persons to achieve the majority's well-being. This philosophy is rightly criticized for grave injustice in this regard, and one can see a utilitarian standard in the Nazi experiments, the Tuskegee experiments, and the other research projects.

The real questions in embryo research are: Should the humanity of these embryos be overlooked for research purposes? Are we willing to affirm human dignity, but only selectively, so that the inconvenient are abandoned? Mathews-Roth affirms the higher standard: "Nontherapeutic experiments without truly informed consent are forbidden on older humans; to be ethically consistent, they must also be forbidden on very young ones."

Having looked at past abuses, a society concerned about its ethical standards should look carefully to the future. The unethical research on pre-born human beings, far from solving human problems, will only create more. It will open a Pandora's box of horrors, and create future dilemmas that will continue to sacrifice high standards of ethics to cold utilitarianism.

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