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## FETAL RESEARCH: A VIEW FROM RIGHT TO LIFE TO WRONGFUL BIRTH

We are operating in the real world where thousands of fetuses will be destroyed as a result of abortion while untold thousands of other fetuses, which are intended to go to term, will suffer risk of death and injury as the result of some potentially controllable factors. It is our responsibility to this latter class that moved us to advocate that *some* research on the about-to-be-aborted fetus is morally necessary.<sup>1</sup>

The scientist labors all day in the comforting womb-like insulation of his laboratory, unconcerned and untouched by the flurry of activity circulating in the community about his research subject. The legislator, the politician, on the other hand, must react and enact according to the tempo of that activity. The issue is fetal research. The present result is an unprecedented intrusion by the legislator into the laboratory. The informed scientist slowly emerges from his protected recesses, speaks his piece and the contest begins.

The fetal research controversy plaguing the country today<sup>2</sup> is largely a result of two factors: the Supreme Court decision<sup>3</sup> legalizing abortion and the refusal to accept this determination by a large, vocal segment of the society. The legalization of abortion has given the scientific community unprecedented opportunities to research on subjects largely unavailable before. These exciting opportunities are threatened by legislative proscription, both on the state and federal level.<sup>4</sup> Before the abortion decision, researchers experimented unhampered on fetal remains and produced important scientific advancements.<sup>5</sup> Now, the concern for the integrity of the abortus as a research subject is overshadowing the quest for knowledge so vital to the goal of preventing and treating diseases that threaten children's health and survival.<sup>6</sup>

1. Gaylin and Lappe, Letter to the Editor, 236 ATLANTIC 16 (July, 1975).

2. In May, 1974, eight states had anti-fetal experimentation statutes. As of May, 1975, seven additional states have enacted similar legislation. The fifteen states are: California, Illinois, Indiana, Kentucky, Louisiana, Maine, Massachusetts, Minnesota, Mississippi, Montana, Nebraska, Ohio, Pennsylvania, South Dakota, and Utah. Information from Institute of Society, Ethics, and the Life Sciences, (Hastings Center), Hastings-on-Hudson, New York.

3. Roe v. Wade, 410 U.S. 113 (1973).

4. "Roe produced a rash of hastily prepared and often ill-conceived state statutes designed to prohibit the same type of fetal experimentation that had occurred prior to recent liberalized abortion laws." Note, *Fetal Experimentation: Moral, Legal, and Medical Implications*, 26 STAN. L. REV. 1191 (1974).

5. "John Enders of Harvard won the Nobel Prize for learning how to grow polio virus in tissue from aborted fetuses, making possible the development of Salk and Sabin vaccines against polio." G. Omenn, *Scientific Manipulation of the Unborn*, to-be-published paper originally presented at Proceedings, ABA/AMA Medical Legal Symposium, Las Vegas, Mar. 14, 1975 (hereinafter cited as Omenn paper).

6. "Considerable confusion has been caused by the suggestion that no investigation on the fetus can be justified unless it can be shown to be of benefit to the actual fetus studied. In the wider sense it has been interpreted as the need to confine studies only to fetuses affected by the

The controversy has become a contest between the state of the art and the state of the law. The contestants are the researchers and the policymakers, but there is also a heavy involvement of right-to-lifers, ethicists, and the courts. The prize of the contest is not the fetus or the abortus, as might be suspected. Rather it is the individual—the ultimate victim or beneficiary of the research.

This paper will review the contest from various vantage points. It will investigate the status of scientific procedures resulting from research accomplished under prior freedom. It will describe the research community poised on the brink of scientific breakthroughs but threatened with legislative vetoes. It will analyze the present posture of these legislative proscriptions in England and in this country, both federal and state. It will examine the intra-professional debate among the scientists themselves. Lastly it will point up the peculiar dilemma of the individual confronting scientific advancement in the courts. Finally, a proposal for judging the contest will be offered.

#### SCIENTIFIC BACKGROUND

The discussion will first describe the techniques developed from past fetal experimentation, followed by the research in progress which is being threatened by recent statutory or quasi-statutory enactments, both in the United States and abroad. This discussion will focus upon amniocentesis, amnioscopy, and reproductive engineering.

#### *Amniocentesis*

Amniocentesis allows the pregnant woman to learn whether the fetus she carries will suffer from hereditary defects.<sup>7</sup> The process is a relatively simple one<sup>8</sup> but not without some attendant dangers.<sup>9</sup> Because of these potential harms, amniocentesis is performed only when there is grounds to suspect that the fetus may have a serious genetic disorder. If the parents have previously

condition under investigation. Interpreted literally, it is unlikely that any clinical research could ever start." Taped Discussion, *New Horizons in Medical Ethics — Research Investigations and the Fetus*, 2 BRIT. MED. J. 464, 465 (1973).

7. See *Ethics of Selective Abortion*, 4 BRIT. MED. J. 676 (1974); Omenn paper, *supra* note 5; Note, *Fetal Experimentation: Moral, Legal, and Medical Implications*, 26 STAN. L. REV. 1191 (1974); Report, BMA Annual Scientific Meeting, 3 BRIT. MED. J. 238 (1974); Milunsky, *Role of Prenatal Genetic Studies*, 288 N. ENGL. J. MED. 1412-13 (1973); Motulsky, *Brave New World?*, 185 SCIENCE 653 (1974).

8. Culliton, *Fetal Research (II): The Nature of a Massachusetts Law*, 187 SCIENCE 411, 412 (1975). See also Omenn paper, *supra* note 5, at 3.

9. See, e.g., *Ethics of Selective Abortion*, 4 BRIT. MED. J. 676 (1974), it may precipitate a spontaneous abortion, and interview with Gilbert S. Omenn, M.D., Ph.D., Dept. of Med., Univ. of Wash., in Las Vegas, Mar. 15, 1975, it may result in hemorrhage, miscarriage, infection, and damage to the fetus, and Omenn paper, *supra* note 5, at 5, ". . . that twins may be present and either go undetected or not both be sampled . . . that the cells might not grow up in the laboratory . . . and that all the conditions not tested for and not testable may still occur, just as in any other pregnancy."

given birth to an abnormal child, if there is a family history of abnormality,<sup>10</sup> or if the pregnant woman is over age 40, the procedure is advisable.<sup>11</sup> When one of these situations exists, a sample of the amniotic fluid is extracted from the uterus with a needle during the fifteenth or sixteenth week of pregnancy. The cells are then grown on a culture medium for two to three weeks, and sometimes for as long as six weeks, and studied for chromosomal or enzymatic abnormalities.<sup>12</sup>

At the present time, amniocentesis is being used primarily to test for four disorders: chromosomal abnormalities such as Down's syndrome (mongoloidism);<sup>13</sup> X-linked disorders, such as Duchenne muscular dystrophy<sup>14</sup> or hemophilia,<sup>15</sup> where determination of the sex of the fetus is a guide for action;<sup>16</sup> metabolic disorders, such as Tay-Sach's disease, in which diagnosis depends on assay of a specific enzyme;<sup>17</sup> and malformations such as spina bifida in which a raised alpha-fetoprotein level is almost certainly diagnostic.<sup>18</sup>

Amniocentesis can be used to inform the pregnant woman whether her fetus is affected by one of the testable categories, yet it cannot be used to tell her whether the fetus is normal in other respects.<sup>19</sup> In addition, if one of the testable disorders is discovered, it cannot, as yet, be corrected *in utero*.<sup>20</sup> As a consequence, amniocentesis is presently used as a genetic counseling tool and "all that can be offered should the fetus be found to be abnormal is termination of the pregnancy, with the option to try again."<sup>21</sup>

### *Amnioscopy*

The amnioscope, although still largely experimental in nature,<sup>22</sup> is an instrument which is inserted into the uterus, providing a view of the fetus. Just recently, this device has become extremely beneficial in diagnosing thalassemia<sup>23</sup> in the developing fetus. In order to test for thalassemia, a sample of fetal

10. *Ethics of Selective Abortion*, 4 BRIT. MED. J. 676 (1974).

11. Omenn paper, *supra* note 5, at 4.

12. *Id.* at 3.

13. *Ethics of Selective Abortion*, 4 BRIT. MED. J. 676 (1974). See also Omenn paper, *supra* note 5, at 3.

14. *Ethics of Selective Abortion*, 4 BRIT. MED. J. 676 (1974).

15. Omenn paper, *supra* note 5, at 11.

16. "Determination of the sex of a fetus is already feasible with amniocentesis, and this makes possible sex choice by selective abortion." Motulsky, *Brave New World?*, 185 SCIENCE 653, 659 (1974).

17. *Id.* at 3. See also *Ethics of Selective Abortion*, *supra* note 14.

18. *Ethics of Selective Abortion*, *supra* note 14.

19. Interview with Dr. Omenn, *supra* note 9.

20. Mainly because such treatment calls for true genetic engineering, a field still in its infancy. See Omenn paper, *supra* note 5, at 20, 21.

21. *Id.* at 4.

22. *Id.* at 5. See also Culliton, *Fetal Research: The Case History of a Massachusetts Law*, 187 SCIENCE 237, 238 (1975) and Culliton, *Fetal Research (II): The Nature of a Massachusetts Law*, 187 SCIENCE 411, 412 (1975) and Report, BMA Annual Scientific Meeting, 3 BRIT. MED. J. 238 (1974).

23. Thalassemia is an anemia of two types: thalassemia minor, the unaffected carrier heterozygous condition, and thalassemia major, the affected homozygous condition. A person

blood is required.<sup>24</sup> The amnioscope with a needle attached to it is inserted in the uterus and a sample of fetal blood from the fetal vein in the placenta is obtained.<sup>25</sup> If there was no way to see inside the uterus, there would be no way to obtain the fetal blood sample. The risk of injuring the fetus with the needle would be too great. If thalassemia is diagnosed from the sample, this information is passed on to the pregnant woman. Amniocopy provides yet another tool for prenatal genetic diagnosis and subsequent genetic counseling.<sup>26</sup>

### *Reproductive Engineering*

Reproductive engineering is the term applied to a broad range of artificial interference with the natural process of fertility.<sup>27</sup> Included are contraception, sterilization, abortion, artificial insemination, sperm banks, *in vitro* fertilization and embryo transplantation.<sup>28</sup> The last four categories are of particular interest because they are, at this time, the most controversial.<sup>29</sup> Artificial insemination<sup>30</sup> is typically the prescribed reproductive procedure in cases of male infertility<sup>31</sup> but it also presents a reproductive alternative to couples who carry the same recessive gene likely to produce genetically defective offspring.<sup>32</sup> In such AID<sup>33</sup> cases, the sperm bank plays a dominant role. Sperm banks are also the insurance mechanism for men undergoing vasectomy procedures for birth control reasons.<sup>34</sup> *In vitro* fertilization and embryo transplantation<sup>35</sup> in humans are technically possible now<sup>36</sup> but extensive use of such procedures in the near future is questionable.<sup>37</sup>

with thalassemia major suffers from pallor, fatigue, weakness, a muddy yellow color of the skin, enlargement of the heart and a thinning of the inner and outer tables of the skull. The condition is prominent in populations from the Mediterranean Sea area. Patients with thalassemia major rarely survive to adulthood. STEADMAN'S MEDICAL DICTIONARY 1518-19 (20th ed. 1961).

24. Culliton, *Fetal Research (II): The Nature of a Massachusetts Law*, 187 SCIENCE 411, 412 (1975).

25. *Id.*

26. Omenn paper, *supra* note 5, at 5.

27. *Id.* at 15.

28. *Id.*

29. For a resume of abortion techniques in this country and their ethical implications and legal ramifications in the area of fetal research, see Note, *Fetal Experimentation: Moral, Legal, and Medical Implications*, 26 STAN. L. REV. 1191 (1974).

30. Artificial insemination is the term used when the woman's ova is fertilized with sperm other than her husband's. See generally Motulsky, *Brave New World?*, 185 SCIENCE 653 (1974).

31. *Id.* at 660. "Studies have shown that most couples using artificial insemination prefer it to adoption." Frankel, *Role of Semen Cryobanking in American Medicine*, 3 BRIT. MED. J. 619, 620 (1974).

32. Motulsky, *supra* note 30, at 661.

33. This is the typical abbreviation for artificial insemination with donor sperm. *Id.* at 660.

34. *Id.* at 661. See also Frankel, *supra* note 31.

35. *In vitro* fertilization and embryo transplantation is the procedure whereby the human oocyte is fertilized in the laboratory and subsequently implanted in the patient's uterus. Report, BMA Annual Scientific Meeting, 3 BRIT. MED. J. 238 (1974).

36. In fact, it has been reported that "three children, apparently normal, were alive in the United Kingdom and Western Europe after embryo transplantation." *Id.* This unverified report has not gone uncriticized. See Omenn paper, *supra* note 5, at 16.

37. Cf. Hecht & Lappe, (Letter to the Editor), *Moratorium on Human Zygote Implantation*, 287 N. ENGL. J. MED. 672 (1972).

## THE RESEARCH THREATENED BY LEGISLATION

Despite the exciting possibilities offered by these scientific advances,<sup>38</sup> future experimentations in the area are either threatened<sup>39</sup> or already severely curtailed.<sup>40</sup> Researchers are not only experiencing prohibitions against their life work<sup>41</sup> but are suffering losses of research grants<sup>42</sup> and, in one case, being criminally prosecuted.<sup>43</sup> Before evaluating the wisdom of these governmentally imposed prohibitions, it is essential to look at exactly which investigations are threatened. This discussion will concentrate on those investigations discussed in the current journals and papers.<sup>44</sup>

One scientist<sup>45</sup> feels that fetal experimentation can answer many questions as yet unanswered, about organ transplants. "If we could understand how the mother's body avoids rejection of the fetus, we might have crucial clues to understand how to prevent rejection of organ transplants and to understand why the body tolerates rapidly dividing tumor cells instead of destroying them."<sup>46</sup> Other scientists are interested in using pre-viable fetuses to develop and test an artificial placenta. In theory, such a device would enable newborn infants suffering from Respiratory Distress Syndrome to live long enough to overcome the condition.<sup>47</sup> One researcher would like to see

38. For an examination of the results of fetal experimentation over the past 20 years, see Note, *Fetal Experimentation: Moral, Legal, and Medical Implications*, 26 STAN. L. REV. 1195-1197 (1974).

39. E.g., Dept. of Health, Education and Welfare Protection of Human Subjects, Proposed Policy, 39 Fed. Reg. 30648 (1974), [hereinafter referred to as HEW Proposals].

40. National Research Act, Pub. L. No. 93-348 (July 12, 1974). This law declared a moratorium on experimentation with a living fetus pending recommendations of the National Commission for the Protection of Human Subjects, to be received in May, 1975. This Commission has just recently made its report. See *Research on Fetuses: Moratorium Ends*, 107 SCIENCE NEWS 285 (1975). "The recommendations . . . become effective as soon as the secretary of HEW . . . sets forth regulations based on them. They would affect almost all fetal research, since most of it is federally funded." *Id.* The Commission's deliberations and recommendations have been published in *Fetal Research*, 5 HASTINGS CENTER REPORT 41-46 (June, 1975). See also *infra* notes 65, 71, 73, 77, 83, and 158.

41. Culliton, *Fetal Research (II): The Case History of a Massachusetts Law*, 187 SCIENCE 411, 412 (1975).

42. "(T)he Secretary may not conduct or support research in the United States or abroad on a living human fetus, before or after the induced abortion of such fetus, unless such research is done for the purpose of assuring the survival of such fetus." (Emphasis added.) National Research Act, Pub. L. No. 93-348 (July 12, 1974).

43. Four Boston City Hospital scientists are now awaiting trial in Massachusetts for violating an ancient grave-robbing statute for transporting tissue from aborted fetuses to a research laboratory. See Culliton, *Fetal Research (II): The Nature of a Massachusetts Law*, 187 SCIENCE 411 (1975); Omenn paper, *supra* note 5, at 14; and Gaylin and Lappe, *Fetal Politics: The Debate on Experimenting with the Unborn*, 235 ATLANTIC 66 (May, 1975). (See also *infra*, section titled "The Cases".)

44. For a comprehensive catalog of research projects utilizing human fetuses, fetal tissue and fetal material, see *The Use of Fetuses and Fetal Material for Research*, Report of the Advisory Group, Dept. of Health and Social Security, Scottish Home and Health Dept., Welsh Office, London (1972), Appendix 2, at 13 [hereinafter referred to as English Guidelines].

45. Gilbert S. Omenn, M.D., Ph.D., Assoc. Prof. Of Med., Div. of Med. Genetics, Univ. of Washington.

46. Omenn paper, *supra* note 5, at 12.

47. Note, *Fetal Experimentation: Moral, Legal, and Medical Implications*, 26 STAN. L. REV. 1191, 1196 (1974).

more sensitive *in utero* tests developed to permit detection of heterozygote carriers.<sup>48</sup> He posits that systematic selective abortion of the carriers could completely eliminate cystic fibrosis, as one example, in forty years.<sup>49</sup>

Many scientists are concerned with experimental subjects which can only be investigated in fetuses scheduled for abortion.<sup>50</sup> The possibility of detecting sickle cell anemia in the early months of pregnancy is one such subject.<sup>51</sup> Another is the need to know whether immunization vaccines (for example, rubella or smallpox) will affect the fetus if administered to a pregnant woman. Here the question under investigation is, does the vaccine cross the placenta and if so, what is the effect on the fetus.<sup>52</sup> Still others want to develop increased flexibility in the amnioscope, not only in its usefulness, but in the instrument itself.<sup>53</sup> At present it is inserted into the uterus by a flexible cannula, but the scope itself is a glass rod.<sup>54</sup> "(W)hat researchers need is an amnioscope that is flexible and has a wide angle lens."<sup>55</sup>

These examples are generally being offered in the public forum to defend freedom of research opportunity.<sup>56</sup> Hence this review does not purport to be complete, just timely. These articulations by scientists are important. They must come out of their laboratories, no matter how reluctantly,<sup>57</sup> to defend

48. Presumably, this would be an extension of the testable genetic traits now possible with the technique of amniocentesis. Kass, *The New Biology: What Price Relieving Man's Estate?*, 1974 SCIENCE 779, 781 (1971).

49. *Id.*

50. Gaylin and Lappe, *Fetal Politics: The Debate on Experimenting with the Unborn*, 235 ATLANTIC 66 (May, 1975); Motulsky, *Brave New World?*, 185 SCIENCE 653 (1974); and Omenn paper, *supra* note 5. And see Culliton, *Fetal Research (II): The Nature of a Massachusetts Law*, 187 SCIENCE 411 (1975). For an in-depth review of one important pre-abortion experiment that has been concluded and published see Culliton, *Grave-Robbing: The Charge Against Four from Boston City Hospital*, 186 SCIENCE 420 (1974). For the published results of the research project itself, see Philipson, Sabath and Charles, *Transplacental Passage of Erythromycin and Clindamycin*, 288 N. ENGL. J. MED. 1219 (1973).

51. Presumably this would involve further experimentation with the still-developing uses of amniocopy. See Motulsky, *Brave New World?*, 185 SCIENCE 653, 660 (1974); Omenn paper, *supra* note 5, at 5; and Culliton, *Fetal Research (II): The Nature of a Massachusetts Law*, 187 SCIENCE 411, 412 (1975).

52. Gaylin and Lappe, *Fetal Politics: The Debate on Experimenting with the Unborn*, 235 ATLANTIC 66, 70 (May, 1975).

53. Dr. David Nathan and Dr. Fredric D. Frigoletto made these goals known during the debate in Massachusetts concerning that state's newly-enacted anti-experimentation statute. Culliton, *Fetal Research (II): The Nature of a Massachusetts Law*, 187 SCIENCE 411, 412 (1975).

54. *Id.*

55. *Id.*

56. For example, Dr. David Nathan and Dr. Fredric D. Frigoletto from Harvard University felt compelled to justify and protect their research in amniocopy when the Massachusetts legislature was in the process of passing its anti-fetal-experimentation statute. Culliton, *Fetal Research (II): The Nature of a Massachusetts Law*, 187 SCIENCE 411 (1975).

57. Dr. David Nathan, a tenured professor and researcher at Harvard University, was instrumental in working out a compromise in the Massachusetts anti-experimentation statute between the legislators and the scientific community. After the Act was passed, he was moved to say, "I'm glad I did what I did, but now I keep waiting for someone to take my place so I can go back to research." Culliton, *Fetal Research: The Case History of a Massachusetts Law*, 187 SCIENCE 237, 241 (1975).

their positions against the rush of legislation<sup>58</sup> banning, or severely restricting, fetal research. But they might be too late. Governmental limitations on scientific inquiry in the area of fetal experimentation are already well underway.

### THE LEGISLATION

Concern for the integrity of the experimental subject is not new.<sup>59</sup> But the ever-widening concern for the integrity of the aborted fetus is perplexing when compared with traditional use of cadavers at medical schools,<sup>60</sup> the Supreme Court's determination that a pre-viable fetus is not a legal entity,<sup>61</sup> and the underlying reasons for a woman seeking an abortion in the first place.<sup>62</sup> Nonetheless, governmental reaction to inflammatory reports of fetal abuse and misuse, both in England<sup>63</sup> and this country<sup>64</sup> has produced harsh consequences for the scientific community in both nations.<sup>65</sup>

58. As of May, 1974, eight states had enacted anti-fetal experimentation statutes. Note, *Fetal Experimentation: Moral, Legal, and Medical Implications*, 26 STAN. L. REV. 1191, 1198 & n.73 (1974). One year later, it is reported that 15 states have enacted such legislation. Gaylin and Lappe, *Fetal Politics: The Debate on Experimenting with the Unborn*, 235 ATLANTIC 66 (May, 1975). See *supra* note 2 for a list of the states.

59. See, e.g., *Human Experimentation: Code of Ethics of the World Medical Association (Declaration of Helsinki)*, 2 BRIT. MED. J. 177 (1964). The Declaration, made before abortion procedures were legitimized, made all non-therapeutic clinical research subject to informed consent. The Declaration is so worded as to preclude any fetal experimentation: "The subject of clinical research should be in such a mental, physical, and legal state as to be able to exercise fully his power of choice." *Id.*

60. See, e.g., Illinois' Use of Bodies of Deceased Persons to Promote Medical Science Statute, ILL. REV. STAT. ch. 91, § 19 (1971), wherein "bodies of . . . deceased persons about to be buried at public expense . . . (can be used) for advancement of medical, anatomical, biological or mortuary science." After such use, the bodies are to be buried or cremated. ILL. REV. STAT. ch. 91, § 22 (1971). Contrast the Illinois anti-fetal experimentation statute: "All tissue removed at the time of abortion shall be submitted for analysis and tissue report to a board eligible or certified pathologist as a matter of record in all cases. *There shall be no exploitation of or experimentation with the aborted tissue.*" (Emphasis added.) ILL. REV. STAT. ch. 38, § 81-18 (1974 Supp.).

61. *Roe v. Wade*, 410 U.S. 113 (1973).

62. Presumably, abortion is sought to terminate forever the chance of a live birth of the conceptus.

63. There have been reports of abortion clinics selling living embryos for research purposes, *Editorial*, 40 MED. LEG. J. 75 (1972), and, in Parliament, rumors of the sale of abortuses for the manufacture of soap and cosmetics. *News & Notes: Parliament*, 4 BRIT. MED. J. 775 (1974).

64. There have been reported cases of abortuses having their chest wall cut in order to observe their heartbeat, Note, *Fetal Experimentation: Moral, Legal, and Medical Implications*, 26 STAN. L. REV. 1191 (1974), and rumors of scientists cutting off fetuses' heads and keeping blood circulating through them. Culliton, *Fetal Research: The Case History of a Massachusetts Law*, 187 SCIENCE 237 (1975).

65. In England, legislation did not result. Instead, the medical community regulates itself under a set of guidelines submitted to, and approved by, the Dept. of Health and Social Security. See English Guidelines, *supra* note 44. In the United States, there is currently a moratorium on fetal experimentation, in effect while an 11-member National Commission for the Protection of Human Subjects in Biomedical and Behavioral Research conducts comprehensive investigations in the area. This Commission will report to the Secretary of HEW at which time firm guidelines will be enacted. See *supra* note 40. In fact, the Commission has submitted its Recommendations



In England, at least, the doctors and scientists, after a two-year inquiry,<sup>66</sup> decided to keep control over fetal experimentation within the purview of their profession.<sup>67</sup> By contrast, in the United States, the medical profession has apparently bowed to governmental regulation in the area.<sup>68</sup> A comparison of the English Guidelines with the HEW Proposals provides an interesting assessment of exactly to what extent the American medical profession has subjugated itself to the "heavy hands of external regulation."<sup>69</sup>

Basically, the English Advisory Group Guidelines advise that if the fetus is viable after separation from the uterus, all efforts must be toward promoting its life.<sup>70</sup> Interestingly, the HEW Proposals make no mention of this alternative.<sup>71</sup> In the English Guidelines, if the fetus is pre-viable after separation, experimentation is allowed unless the parent objects—but no positive consent is required.<sup>72</sup> By contrast, the HEW Proposals prohibit experimentation on the pre-viable fetus unless "the mother and father are legally competent and have given their consent, except that the father's consent need not be secured if his identity or whereabouts cannot reasonably be ascertained."<sup>73</sup> This requirement of positive consent, from both parents,

to the Secretary. *See generally Fetal Research*, 5 HASTINGS CENTER REPORT 41-46 (June, 1975). The Recommendations of the Commission are refreshingly liberal. They urge an end to the moratorium on fetal research and the immediate resumption of funding in the area. They also explicitly permit and encourage all research in the field but with specific guidelines detailed for each area considered. The areas are: a) therapeutic research directed toward the fetus; b) therapeutic research directed toward the pregnant woman; c) non-therapeutic research directed toward the fetus *in utero*; d) non-therapeutic research directed toward the fetus *in utero*; e) non-therapeutic research directed toward the fetus in anticipation of abortion; f) non-therapeutic research directed toward the fetus during the abortion procedure and non-therapeutic research directed toward the non-viable fetus *ex utero*; and g) non-therapeutic research directed toward the possibly viable infant. *Id.* at 45, 46.

66. English Guidelines, *supra* note 44. The Secretary appointed the advisory group in May, 1970. The group issued its report in 1972.

67. *See supra* note 65.

68. HEW Proposals, 39 Fed. Reg. 30648 (1974). *See also supra* note 65.

69. Etzioni, *Sex Control, Science, and Society*, 161 SCIENCE 1107, 1110 (1968).

70. *See* English Guidelines, *supra* notes 65 and 66.

71. HEW Proposals, 39 Fed. Reg. 30648 (1974). *See also supra* note 65. The recently published Recommendations of the National Commission for the Protection of Human Subjects do not take this possibility into consideration either. *See Commission Recommendations*, 5 HASTINGS CENTER REPORT 45 (June, 1975).

72. *See* English Guidelines, *supra* note 44.

73. HEW Proposals, § 46.307(b), 39 Fed. Reg. 30648, 30654 (1974). *See also* the Recommendations of the National Commission for the Protection of Human Subjects as published in *Fetal Research*, 5 HASTINGS CENTER REPORT 41-46 (June, 1975). The Commission was plagued by the issue of consent. It rejected the notion that both mother and father must consent to research which the Commission encourages. Instead, they require the informed consent of the mother (or pregnant woman) and then give the father a veto power over all the endorsed categories of research (except the category of therapeutic research directed toward the pregnant woman). The father's positive consent is not required, but he can effectively prohibit any research, even non-therapeutic research directed toward the pregnant woman. This is a baffling result when considered with the judicially accepted view of the woman's right to privacy over her own body and that line of cases which prohibit a father from interfering with his wife's decision for an abortion or which prevent him from forcing her to abort. Yet the Commission stated in its Deliberations: "In view of the necessary involvement of the woman in such research,

places a great burden on the American researcher, while his English counterpart can proceed with his projects, undeterred, until a parent objects.

The English Guidelines prohibit experimentation on fetuses scheduled for abortion.<sup>74</sup> This prohibition is currently a very controversial issue.<sup>75</sup> Because of its controversial nature it is interesting to see how these Guidelines provide for project review.

It is recommended that the ethics of projects involving use of fetal material should be considered by boards of governors, hospital management committees and similar bodies by the appointment of subcommittees of hospital doctors, some of whom should be experienced in medical research. If central guidance became necessary a small advisory body with representatives from the General Medical Council, College of Obstetricians, Paediatric Association and Medical Research Council might be convened.<sup>76</sup>

Presumably, this informal review procedure would allow reconsideration of the prohibition against experimentation on fetuses scheduled for abortion if the researcher could convince his peers of the scientific necessity of the project and if he could show that it involves no risk to the pregnant woman.

By contrast, the HEW Proposals do not ban outright *in utero* experimentation of fetuses scheduled for abortion if the researcher can show that the activity would benefit the health needs of the mother and the activity would take place at the termination of the pregnancy, not prior to the termination.<sup>77</sup> Just exactly what research was being protected here was unclear. An examination of the Department's reasoning provides few clues. It is simply stated that "such research may produce new technology which will enable

her consent is considered mandatory; in view of the father's possible ongoing responsibility, his objection is considered sufficient to veto." *Id.* at 42.

74. "It is unethical to administer drugs or carry out any procedures during pregnancy with the deliberate intent of ascertaining the harm they might do to the fetus." English Guidelines, *supra* note 44, at 12.

75. Gaylin and Lappe, *Fetal Politics: The Debate on Experimenting with the Unborn*, 235 ATLANTIC 66 (May, 1975).

76. Editorial, *The Use of Human Fetal Material for Research*, 40 MED. LEG. J. 75, 76 (1972).

77. Activities involving fetuses in utero or pregnant women. (a) No activity to which this subpart is applicable, involving fetuses *in utero* or pregnant women, may be undertaken unless: (1) the purposes of the activity is to benefit the particular fetus or to respond to the health needs of the mother, or (2) the activity conducted as part of (but not prior to the commencement of) a procedure to terminate the pregnancy and is for the purpose of evaluating or improving methods of prenatal diagnosis, methods of prevention of premature birth, or methods of intervention to offset the effects of genetic abnormality or congenital injury.

HEW Proposals, § 46.306, 39 Fed. Reg. 30648, 30654 (1974). The National Commission for the Protection of Human Subjects, on the other hand, explicitly endorses such research.

*Non-therapeutic research directed toward the fetus in anticipation of abortion* may be conducted or supported by the Secretary, DHEW, provided such research is carried out within the guidelines for all other non-therapeutic research directed toward the fetus *in utero*. Such research presenting special problems related to the interpretation or application of these guidelines may be conducted or supported by the Secretary,

DHEW, provided such research has been approved by a national ethical review body. *Commission Recommendations*, 5 HASTINGS CENTER REPORT 45 (June, 1975).

countless premature infants to live who now cannot."<sup>78</sup> But the Department, here again, reiterates its stand prohibiting pre-abortion experimentation.<sup>79</sup> The important distinction here is that the more liberalized wording of the HEW Proposals in contrast to the English Guidelines statement, will become law whereas in England it is a professional code only. The opportunity for opening up the discussion in this field is much greater in England than it will be in the States after the Proposals go into effect.

Also of interest is that, in England, all clinical decisions and ethical questions will be considered only by the profession—the Guidelines emphatically keep laymen off the committees which consider these matters.<sup>80</sup> They also rejected the notion of maintaining a standing ethical committee.<sup>81</sup> By contrast, the HEW Proposals devote approximately one half of the statute to setting up a permanent committee structure to oversee experimentation projects.<sup>82</sup> Perhaps this is based on the inherently American notion that everything can be solved by a committee. No matter what the origin of the concept may be, after reading the proposal on committee structure it becomes apparent that any research will be closely monitored, not just by the professional peers of the researcher, but by lawyers, clergymen, ethicists and laymen as well. The only class excluded from the standing Ethical Advisory Board contemplated at this time is the governmental employee.<sup>83</sup> Actually, the proposed monitoring system is two-tiered.<sup>84</sup> All applications or proposals for

78. This language is found in the Prologue to the Proposed Rules. *Id.* at 30651.

79. "It is not intended that this provision be construed to permit fetal research in anticipation of abortion prior to the commencement of the termination procedure itself." *Id.*

80. "Our conclusion was that clinical decisions are the responsibility of the clinician, and that ethical questions are for the profession to consider." English Guidelines, *supra* note 44, at 10.

81. We concluded that it would not be necessary to have a permanent body to handle the limited number of enquiries which are likely to arise. Instead we recommend that arrangements should be made for a small informal body with legal representation and including members drawn from the Medical Research Council, the Royal College of Obstetricians and Gynaecologists, the General Medical Council and the British Paediatric Association to be convened when the need for central advice arises.

*Id.* at 11.

82. HEW Proposals, § 46.304 and § 46.305, 39 Fed. Reg. 30648, 30653 (1974).

83. *Id.* § 46.304(b). It is also interesting to view what the National Commission for the Protection of Human Subjects has recommended to the Secretary, DHEW, on the matter of review. The Commission is obviously very concerned about the monitoring of research projects and consent procedures. In fact, the Commission is still deliberating the final monitoring system it will ultimately endorse. In the meantime, the Commission has apparently adopted the review procedures herein outlined in the HEW Guidelines. The Commission has indicated, however, that it basically favors the idea of a permanent Ethical Advisory Board when it urges the establishment of a National Advisory Council for the Protection of Subjects of Biomedical and Behavioral Research, which is to include "appropriate provision(s) . . . for public attendance and public participation in the national review process." The Commission seemingly aims to insure that no individual nor interest group is offended by a scientist's research proposal. *Commission Recommendations*, 5 HASTINGS CENTER REPORT 46 (June, 1975).

84. Although the monitoring system is two-tiered, it must be kept in mind that even if a research proposal passes at the Ethical Advisory Board level, that is not a guarantee of project approval. The Ethical Advisory Board is simply an advisory body — the funding agency will still determine the final award. *Id.* at 30650. This Kafkaesque morass, by itself, could inhibit the number of research proposals submitted.

research must be submitted to the permanent Ethical Advisory Board<sup>85</sup> and before the project is approved, a local consent committee<sup>86</sup> must be established. The duties of the local consent committee may include, but are not limited to: participation in the actual selection process and securing the consents of the participants in the project, monitoring the progress of the project, actually maintaining periodic contact with the participants, and even includes the authority to terminate the participation of some of the subjects "with or without their consent where conditions warrant."<sup>87</sup>

To date, the Proposals do not stipulate outright who will sit on the local consent committee. They only indicate that the make-up of the committee must be approved by the Secretary and one of the tests for his approval is "whether the committee includes sufficient members who are not engaged in research, development, or related activities involving human subjects."<sup>88</sup> Certainly this language does not limit the committee to simply a peer review board. To be fair, it should be mentioned that this two-tiered monitoring structure does not only apply to fetal experimentation projects. It is also designed to oversee projects involving experimentation on prisoners and the mentally disabled.<sup>89</sup> No value judgment is made here in respect to these two groups. It should be sufficient to point out that the need to protect the integrity of an abortus cannot be so compelling as to warrant such strict monitoring as designed by the HEW Proposals.

The HEW Proposals are very strict and all projects applying for funding would be severely scrutinized on every level. Yet the Proposals do not attempt to preempt state or local legislation in the area of fetal experimentation.<sup>90</sup> Since fifteen states have acted in this area,<sup>91</sup> and at least one city has passed an anti-fetal experimentation ordinance,<sup>92</sup> the restrictions placed upon scientists living in those states, or city, have become so onerous as to place them at a great disadvantage in comparison with colleagues living in states without statutory limitations. One can envision a plethora of equal protection and right to pursue an occupation suit in the near future if the HEW Proposals become law as they now stand.

Of threshold interest is the lack of uniformity in state legislation being enacted. To point up the disparities and varying prohibitions these statutes

85. *Id.* § 46.304.

86. *Id.* § 46.305.

87. *Id.* § 46.305(a)(1)(2).

88. *Id.* § 46.305(b)(5).

89. *Id.* Subpart D (Prisoners as Subjects) and Subpart E (Mentally Disabled as Subjects).

90. "Nothing in this subpart shall be construed as indicating that compliance with the procedures set forth herein will in any way render inapplicable pertinent State or local laws bearing upon activities covered by this subpart." *Id.* § 46.301(b).

91. *See supra* note 2.

92. The Cleveland city council has outlawed research on fetuses completely. Cleveland, Ohio, Ordinance No. 1861-A-73, Dec. 10, 1973. Experimentation Upon a Fetus. "No person shall experiment upon or sell the product of human conception which is aborted, irrespective of the duration of the pregnancy."

have placed upon scientists living within their borders, three state's enactments will be examined: Illinois, California, and Massachusetts.

In Illinois, there is a complete ban on experimentation.<sup>93</sup> "There shall be no exploitation of or experimentation with the aborted tissue."<sup>94</sup> Yet the statute does not define "tissue," nor does it speak to pre-abortion experiments. The specific language of the statute without a definition of terms leaves the researcher in a peculiar dilemma. The California statute is broader.<sup>95</sup> It allows for experimentation on fetal remains, defined as the lifeless product of conception, but the product is not lifeless if there is a discernible heartbeat.<sup>96</sup> This test has been criticized.<sup>97</sup> Interestingly, California does not prohibit experimentation designed to "protect or preserve the life and health of the fetus."<sup>98</sup> Since the statute does not speak to *in utero* experimentation, presumably in California amniocentesis is allowed and perhaps even the development of an artificial placenta would not be prohibited. By contrast, the Illinois researcher would be wary of attempting any experimentation at all.

The Massachusetts statute<sup>99</sup> provides the final step in developing the types of state interference in this area. The Illinois statute is short, summary in nature, and apparently dispositive on the matter. The California statute is broader, as discussed above. The Massachusetts statute is thought to be more "liberal"<sup>100</sup> mainly because it was a compromise measure hammered out between the legislators battling on behalf of their "right to life" constituents and scientists from Harvard fighting to save their research projects from criminal sanction.<sup>101</sup> The legislators were more successful than the scientists who had ventured into unfamiliar territory to plead their case.<sup>102</sup> Basically, the statute prohibits *in utero* experiments and experiments on live fetuses after expulsion from the womb. The scientists managed to preserve amniocentesis

93. Does this mean that a scientist residing in Illinois would be ineligible from the outset from applying for a HEW grant?

94. ILL. REV. STAT. ch. 38, § 81-18 (Supp. 1974).

95. CAL. HEALTH & SAFETY CODE § 25956 (West Supp. 1974).

96. *Id.*

97. "Since heartbeat occurs in the fetus as early as the first month of gestation — long before the fetus becomes viable and even before the mother knows she is pregnant — immediate experimentation is proscribed on virtually all fetuses aborted by hysterotomy." Note, *Fetal Experimentation: Moral, Legal, and Medical Implications*, 26 STAN. L. REV. 1191, 1199 (1974).

98. CAL. HEALTH & SAFETY CODE § 25956 (West Supp. 1974).

99. MASS. GEN. LAWS ch. 112, § 12J (West Supp. 1975).

100. "The Massachusetts law is regarded as more liberal than those of some other states." Culliton, *Fetal Research: The Case History of a Massachusetts Law*, 187 SCIENCE 237, 241 (1975).

101. See *id.* and Culliton, *Fetal Research (II): The Nature of a Massachusetts Law*, 187 SCIENCE 411 (1975). These two articles report the fight behind the legislation in Massachusetts and assess its impact 6 months later.

102. "There they were, some of the biggest names at the Harvard Medical School standing up like schoolboys to describe their work and ask, 'Please, Mr. Legislator, may I go on with what I'm doing?'" Culliton, *Fetal Research (II): The Nature of a Massachusetts Law*, 187 SCIENCE 411 (1975).

and amniocopy procedures as the statute allows for procedures which "do not substantially jeopardize the life or health of the fetus."<sup>103</sup> Unfortunately, the statute further provides that fetuses scheduled for abortion cannot be the subject of experimentation.<sup>104</sup> Apparently the scientists involved in the controversy were not pleased with this prohibition.<sup>105</sup>

This statute presents an interesting anomaly. If a woman who has already conceived an affected child, for example, a child who has thalassemia major,<sup>106</sup> comes in for abortion for fear of having a second affected child, the physician could not perform the amniocentesis procedure to determine if, in fact, the fetus would be affected. On the other hand, if a pregnant woman came in for a routine gynecological check-up she could be solicited as a subject for amniocentesis or amnioscopic procedures. This vagary in the statutory language could not be worked out by compromise.<sup>107</sup> Further, the Massachusetts statute provides that any experimentation on the dead fetus must be conducted only with the consent of the mother.<sup>108</sup> Neither Illinois nor California speak of such consent. Lastly, the Massachusetts statute carries a prison sentence for violation of its provisions<sup>109</sup> whereas Illinois does not indicate violation penalties at all<sup>110</sup> and California specifies that violation constitutes only "unprofessional conduct."<sup>111</sup> To construe the Massachusetts legislation as "liberal" simply because it was a compromise is a misnomer. Any legislation limiting, prohibiting, or criminally punishing fetal experimentation is not liberal. It is professional interference with another profession.

This review of legislation on fetal experimentation shows that the legislators and the federal government are attempting to act in an area in

103. No person shall use any live human fetus, whether before or after expulsion from its mother's womb, for scientific, laboratory, research or other kind of experimentation. This section shall not prohibit procedures incident to the study of a human fetus while it is in its mother's womb, provided that in the best medical judgment of the physician, made at the time of the study, said procedures do not substantially jeopardize the life or health of the fetus, and provided said fetus is not the subject of a planned abortion.

MASS. GEN. LAWS ch. 112, § 12J (West Supp. 1975).

104. *Id.*

105. "David Nathan, who says he has personal reservations about abortion, is, nevertheless, one of the many, many fetal researchers who believe it is morally justifiable to do research on antenatal diagnosis of blood diseases, particularly sickle cell anemia and thalassemia, is a case in point. Research on the effects of virus vaccines on the fetus is another." Culliton, *Fetal Research (II): The Nature of a Massachusetts Law*, 187 SCIENCE 411, 412 (1975).

106. See *supra* note 23 for a description of thalassemia.

107. Dr. Nathan indicated that if I could diagnose sickle cell anemia and thalassemia and other disorders *in utero*, I'd be preventing more abortions than they ever could. We have women who have an abortion because they don't want to risk having an afflicted child. With antenatal diagnosis, I could tell them, three times out of four, to go ahead and have the baby. They listened but were not persuaded.

Culliton, *Fetal Research: The Case History of a Massachusetts Law*, 187 SCIENCE 237, 238 (1975).

108. MASS. GEN. LAWS ch. 112, § 12J (West Supp. 1975).

109. "Whoever violates the provisions of this section shall be punished by imprisonment in a jail or house of correction for not less than one year nor more than two and one-half years or by imprisonment in the State prison for not more than five years." *Id.*

110. ILL. REV. STAT. ch. 38, § 81-18 (Supp. 1974).

111. CAL. HEALTH & SAFETY CODE § 25956 (West Supp. 1974).

which they have little or no expertise and little if any professional judgment. To attempt to enter a field as complex as scientific experimentation of the unborn is presumptive, unprofessional, and potentially harmful not only to the scientists, but to future generations of infants who will not benefit from knowledge summarily prohibited now. The states are acting too quickly and with so little uniformity as to prejudice an entire profession simply on the basis of happenstance of location. The federal government, the major funding agency in all these endeavors, is attempting to legislate nation-wide without providing that fundamental safeguard required of federal paternalism: preemption. The entire area of fetal experimentation should be returned to the scientific community for self-regulation. That the community has built-in mechanisms for dealing with this controversial subject will be shown in the next section.<sup>112</sup> That section will treat the divisions within the scientific community itself: physician pitted against physician; physician at odds with scientist; scientist disagreeing with scientist. The debate within the community will or can provide all the safeguards the public requires for protection and it can do this much more knowledgeably than any layman or legislator can ever attempt to do.

#### THE DEBATE IN THE MEDICAL PROFESSION:

Physician v. Physician

Physician v. Scientist

Scientist v. Scientist

#### *Investigation v. Implementation*

The freedom of the scientist to investigate is at issue. If scientific investigations have resulted in seemingly conflicting goals within the society, it is not a new problem.<sup>113</sup> The results of free exploration are ultimately safeguarded at the implementation level.<sup>114</sup> This very safeguard begins within the profession. One scientist<sup>115</sup> in 1972 called for a nation-wide moratorium on human zygote implantation and the exertion of moral pressure by colleagues of the researchers to stop such experimentation until supportive primate evidence could be gathered.<sup>116</sup> That same scientist is currently making

112. "[O]nly an extension of the existing codes and mechanisms of self-control will ultimately protect science from a societal backlash and the heavy hands of external regulation." Etzioni, *Sex Control, Science, and Society*, 161 *SCIENCE* 1107, 1110 (1968).

113. "On the one hand, we seek to control population growth by lowering fertility; on the other hand, we develop techniques to enable every infertile woman to bear a child. On the one hand, we try to extend the lives of individuals with genetic disease. On the other, we wish to eliminate deleterious genes from the human population." Kass, *The New Biology: What Price Relieving Man's Estate?*, 174 *SCIENCE* 779, 782 (1971).

114. "The applications of scientific findings are not determined by the scientists, but by society, politicians, corporations, and the citizens . . . . Scientists split the atom, but they did not decide whether particles would be used to produce energy to water deserts or superbombs." Etzioni, *supra* note 112, at 1110.

115. Marc Lappe, Ph.D., Associate, Institute of Society, Ethics and the Life Sciences, Hastings-on-Hudson, New York.

116. Lappe, *Moratorium on Human Zygote Implantation*, 287 *N. ENG. J. MED.* 672 (1972).

a plea for retraction of all legislation prohibiting experimentation on fetuses scheduled for abortion.<sup>117</sup> In essence he is saying that freedom of scientific inquiry for knowledge's sake should not be prohibited, but when it comes to applying that knowledge to an individual—in this case, the woman with blocked tubes who wants to be pregnant—we should proceed much more cautiously. Safeguards such as these within the profession should not be minimized or ignored.

### Embryo Transplantation

The intra-professional opinion on the embryo transplant issue is not uniform. The opinion expressed above is one view. Another is the rejection of the notion that “to be moral, human reproduction must be coital.”<sup>118</sup> This view could well apply to artificial insemination as well as *in vitro* fertilization and embryo transplants. One scientist has even gone far beyond his colleague's expressions when he wrote: “It is difficult to agree with those who suggest that normal procreation is human and fertilization *in vitro* is inhuman. I consider novel reproductive techniques as a more human activity than making babies in the usual way.”<sup>119</sup> These statements might, on their face, appear to indeed forecast a Brave New World in the near future. But what this scientist is really protecting is the right of a woman with blocked fallopian tubes to be pregnant, with her own ova fertilized by her husband's sperm.<sup>120</sup> With the current dearth of adoptable children today, these now-futuristic procedures give hope to the 30 percent of married couples who experience reproductive difficulties.<sup>121</sup> But not all scientists agree. Some have doubts about the “humanness” of interfering in the reproductive process.<sup>122</sup>

### Amniocentesis

There continues to be a debate in the scientific community even concerning amniocentesis. The question is not whether the procedure itself is moral or ethical, but rather when it should and should not be utilized as a genetic counseling tool. Some physicians feel it should not be utilized if the parents, prior to the procedure have rejected the option of abortion in the event the fetus is tested as abnormal.<sup>123</sup> The rationale underlying this policy is

117. Gaylin and Lappe, *Fetal Politics: The Debate on Experimenting with the Unborn*, 235 ATLANTIC 66 (May, 1975).

118. See Prof. Bevis' remarks at the British Medical Association Annual Scientific Meeting as reported in 3 BRIT. MED. J. 238 (1974).

119. Motulsky, *Brave New World?*, 185 SCIENCE 653, 661 (1974).

120. See *supra* note 35.

121. Frankel, *Role of Semen Cryobanking in American Medicine*, 3 BRIT. MED. J. 619 (1974).

122. “Is there perhaps some wisdom in that mystery of nature which joins the pleasure of sex, the communication of love, and the desire for children in the very activity by which we continue the chain of human existence?” Kass, *The New Biology: What Price Relieving Man's Estate?*, 174 SCIENCE 779, 785 (1971).

123. “(I)t has been and continues to be our policy to discourage amniocentesis in circumstances in which abortion is definitely rejected as a possible alternative.” Doctors Epstein and Golbus, Letter to the Editor, 288 N. ENGL. J. MED. 1413 (1973).



the initial distaste for possibly "generating tremendous psychologic stress in families who will have to go through more than 1/2 of the pregnancy knowing that their child will be abnormal . . ." <sup>124</sup> The critics of this position claim just the opposite. They claim parents, in order to make a truly informed choice, must have all the information made available to them. <sup>125</sup> Besides, the critics point out that when amniocentesis is performed on "high-risk" <sup>126</sup> couples, the diagnosis of the fetus is 95 percent normalcy. <sup>127</sup>

This has two basic ramifications. First, if the woman feared a defective child, the diagnosis of an unaffected child would mean that the second half of her pregnancy would be worry-free. <sup>128</sup> Second, genetic counseling for all "high-risk" couples would actually "save" children from abortion. <sup>129</sup>

Another scientist <sup>130</sup> forecasts additional problems regarding amniocentesis other than the "will abort, won't abort" considerations discussed above. He envisions insurance companies withholding benefits from parents who bear a sick child when advised, after amniocentesis, not to reproduce. <sup>131</sup> He suggests other problems when milder genetic defects are diagnosed and questions if these disorders should result in abortion. <sup>132</sup> The problem can be taken two steps further: if selective abortion becomes widely practiced, will society's tolerance to living defectives be reduced? And lastly, if a defective fetus can be destroyed, what about a newborn defective child? "Could we be at the top of a slippery slope?" <sup>133</sup>

Considerations such as these are more likely to emerge from the people working in the particular field. Complicated ramifications from scientific procedures and innovations are not readily recognized nor anticipated by the layman or the politician.

### *Semen Banks*

Another area being widely discussed in the public forum concerns semen banks. <sup>134</sup> Interestingly here there is not much debate, <sup>135</sup> but rather a general

124. *Id.*

125. Milunsky, Letter to the Editor, *id.* at 1412.

126. *See supra* note 9 and accompanying text.

127. Milunsky, Letter to the Editor, 288 N. ENGL. J. MED. 1412 (1973).

128. "(M)ost amniocenteses give normal results, and . . . the total happiness generated in families receiving such results outweighs the anguish of the rare couple who know that they will have an affected child but choose not to abort." Motulsky, *Brave New World?*, 185 SCIENCE 653, 658 (1974).

129. *See id.* and Omenn paper, *supra* note 5, at 4.

130. Motulsky, *supra* note 128.

131. *Id.* at 657.

132. *E.g.*, Klinefelter's or Turner's syndromes, and cleft palate. *Id.*

133. *Ethics of Selective Abortion*, 4 BRIT. MED. J. 676 (1974). *See also* Motulsky, *supra* note 128.

134. *See, e.g.*, Frankel, *Role of Semen Cryobanking in American Medicine*, 3 BRIT. MED. J. 619 (1974); Louros, *Against Heterologous Insemination*, 58 INTERNATIONAL SURGERY 190 (1973); Motulsky, *Brave New World?*, 185 SCIENCE 653 (1974); *Law and Ethics of A.I.D. and Embryo Transfer*, CIBA FOUNDATION SYMPOSIUM 17 (New Series 1973).

135. *But see* Louros, *supra* note 134. "Frozen sperm banks are, in my opinion, unacceptable

call for governmental regulation. The defenders of the status quo regarding these banks are unusually silent, perhaps because their activities at the present time are for the most part *sub rosa*.<sup>136</sup> One author<sup>137</sup> has recently described perplexing questions surrounding semen cryobanking activities which need immediate attention and guidelines. How does the doctor determine which couples are suitable for donor insemination?<sup>138</sup> How does the doctor obtain truly informed consent, from the receiving couple concerning the hazards involved, and from the donor?<sup>139</sup> Who should request the consent: the doctor or the bank? Other perplexing questions involve donor screening for genetic defects, medical and genetic history,<sup>140</sup> and the problems of the paid donor.<sup>141</sup> Many unresolved legal problems arise also, as to the illegitimacy of the offspring, its inheritance rights, and whether its birth certificate should include the name of the biologic father.<sup>142</sup> Another scientist feels that the long-term storage of sperm has not been sufficiently tested as yet and until it has been, he suggests caution in its use.<sup>143</sup> The politicians, in their rush to legislate in the area of fetal experimentation, might first heed the call of the medical profession to regulate areas which it feels are potentially dangerous. Semen banking is one such area.<sup>144</sup>

### *The World Gene Pool and Natural Selection*

One last major concern within the scientific community will be treated here and that is the debate among the geneticists<sup>145</sup> concerning the long-range effect of genetic<sup>146</sup> and reproductive engineering on the world gene pool. Limiting this discussion to the effects of reproductive engineering as treated in

and (the) most repulsive forms of taking advantage of a product of high biological and hereditary value and are a token of contempt for man." *Id.* at 191.

136. Interview with Dr. Omenn, *supra* note 9.

137. Mark S. Frankel, Research Associate, Program of Policy Studies in Science and Technology, George Washington University, Washington, D.C.

138. Are such guidelines as "stable marriage" and "emotionally mature" sufficient tests? Frankel, *Role of Semen Cryobanking in American Medicine*, 3 *BRIT. MED. J.* 619, 620 (1974).

139. Does the donor really know, or has he truly consented to the use of his semen for inseminating a woman other than his wife? *Id.*

140. This is of concern because "the transmission of gonorrhoea by artificial insemination has been reported." *Id.* at 621.

141. "For example, how likely is it that a donor with a drug habit, using drugs that may cause permanent chromosomal damage, will seek remuneration of his semen as a way of maintaining his habit?" *Id.*

142. See generally, *Law and Ethics of A.I.D. and Embryo Transfer*, CIBA FOUNDATION SYMPOSIUM 17 (New Series 1973).

143. Motulsky, *Brave New World?*, 185 *SCIENCE* 653, 661 (1974).

144. "There are many questions that have not been satisfactorily answered by existing sperm banks and none of the banks, as far as I know, have been licensed by any federal or state agency." *Id.*

145. See, e.g., Motulsky, Fraser and Felsenstein, *Public Health and Long-Term Genetic Implications of Intrauterine Diagnosis and Selective Abortion*, 7 *BIRTH DEFECTS* 22 (April, 1971); Hirschhorn, *Practical and Ethical Problems in Human Genetics*, 8 *BIRTH DEFECTS* 17 (July, 1972); *Ethics of Selective Abortion*, 4 *BRIT. MED. J.* 676 (1974); and Kass, *The New Biology: What Price Relieving Man's Estate?*, 174 *SCIENCE* 779 (1971).

146. This paper has not attempted to cover the area of genetic engineering which mainly concerns gene therapy (introducing genes into cells by viral transduction) and nuclear

this article, effects on the world gene pool are possible from two different vantage points. On the one hand is the reproductive capabilities of heretofore incapacitated individuals owing to medical advances in treatment of certain disorders. Examples are the post-natal treatment of PKU, diabetes, cleft palate and hemophilia.<sup>147</sup> As a result of these medical advances, there is a steadily increasing frequency of abnormal, mutant genes being propagated in the world population. On the other hand is the elimination of abnormal genes, through the use of selective abortion, owing to medical advances such as amniocentesis, which purify the gene pool. This is true for the selective abortion of affected fetuses (homozygous), but not necessarily if selective abortion is widely practiced on carrier fetuses (heterozygous).<sup>148</sup> In certain cases, it has been discovered that these heterozygotes carry important immunizations that unaffected homozygotes do not. One such example is the carrier of sickle cell anemia who has strong immunization against malaria.<sup>149</sup> One geneticist feels that to eliminate the heterozygote carrier in such a circumstance would be very harmful.<sup>150</sup> Others feel that, under modern conditions, heterozygote advantages are not likely to play an important role.<sup>151</sup>

The issue regarding the world gene pool controversy is to what extent man's interference in the pool will effect natural evolution and natural selection. There is as yet no answer to this very disturbing question. One guess is that artificial modifications will have no effect on true natural evolution because "the 'natural' environment necessarily includes man-made changes in the medical, technical and social spheres."<sup>152</sup> This seems to be based on the accepted notion that "no matter how we change the genetic make-up of individuals, we cannot do away with natural selection."<sup>153</sup>

Within the scientific community and medical profession, the moral and ethical debate will continue to flourish as new experimental fields open up or

transplantation (also called cloning, whereby the nucleus of an unfertilized egg is asexually re-nucleated and an identical individual results). See Kass, *The New Biology: What Price Relieving Man's Estate?*, 174 SCIENCE 779 (1971) and Omenn paper, *supra* note 5.

147. Hirshhorn, *supra* note 145, at 18, 26.

148. "To really diminish the frequency of a recessive gene in the population it would be necessary to detect and abort heterozygous carriers, as well as the very much less frequent homozygous affected fetuses." Letter from Gilbert Omenn, M.D., Ph.D., Dept. of Medicine, Division of Medical Genetics, University of Washington, to the author, dated April 28, 1975, now on file in the Chicago-Kent Law Review Office.

149. For example, individuals homozygous for the gene coding for sickle-cell hemoglobin invariably develop sickle-cell anemia which is generally fatal before the reproductive years. Heterozygotes, for the gene are, however, protected more than normals from the effects of the most malignant form of malaria. It has been shown that women who carry the gene in single dose have a higher fertility in malarial areas than do normals.

Hirshhorn, *supra* note 145, at 23.

150. *Id.* at 24.

151. Motulsky, Fraser and Felsenstein, *supra* note 145 at 31. See also Miller, *Discussion of Symposium Papers*, 7 BIRTH DEFECTS 33, 34 (April, 1971).

152. Hirshhorn, *supra* note 145, at 18.

153. *Id.* quoting C.C. Li in his presidential address to the American Society of Human Genetics in 1960, at 28.

become available. The topics discussed above, experimentation versus implementation, *in vitro* fertilization and human embryo transplantation, the pros and cons of amniocentesis, semen banking, and the effect of reproductive and genetic engineering on the world gene pool, all clearly indicate that the doctors and the scientists are not only professionals, but are human beings as well, with moral and ethical standards as high or higher than those who are attempting and succeeding in proscribing their work. But this is not to say that there should be no accountability in science. Quite the contrary. The thesis offered here is simply this: give the research opportunities back to the medical profession where they properly belong and let the self-regulating mechanisms within the profession struggle with the moral and ethical considerations upon which most of the current legislation is founded. These research opportunities will result in knowledge and procedures which will eventually filter down to application on the individual level. When this occurs, accountability will be assured. The individual, if harmed by the new knowledge, must be guaranteed a cause of action against the wrongdoer, when the harm results from negligent application of that knowledge or those procedures. The following section will indicate how this can be done.

#### THE CASES

For obvious reasons, there are no cases, historically, dealing with fetal experimentation. At the present time, however, there is one criminal case pending in Massachusetts<sup>154</sup> which directly concerns the fetal research field and which should give each scientist pause for concern. In this case, *Commonwealth v. Berman*, four scientists at Boston City Hospital have been indicted for conducting a study on pregnant women scheduled for abortion. The researchers were attempting to determine the differences of metabolizing antibiotics between pregnant women and non-pregnant women.<sup>155</sup> For this study they obtained the consent of the women involved. After the pregnant women were aborted, the scientists, as a matter of course, wanted to determine the effects of the antibiotics on the fetuses. They examined and analyzed the effect of the drugs on these fetuses without maternal consent, determined which ones crossed the placenta and published their report,<sup>156</sup> unaware of any legal consequences which might, and indeed which did, follow. They were subsequently indicted under an 1814 Massachusetts grave robbing statute and their fate is awaiting trial now.<sup>157</sup>

We can expect similar cases in the future when prosecutions begin under the newly-enacted state legislations in the area. What is also of concern here,

154. *Commonwealth v. Berman*, Crim. No. 81821 (Super. Ct. Suffolk Cty., Mass., filed April 17, 1974). See also Culliton, *Grave Robbing: The Charge against Four From Boston City Hospital*, 186 *SCIENCE* 420 (1974).

155. *Id.* at 421.

156. See *id.* at 421 and Philipson, Sabath and Charles, *Transplacental Passage of Erythromycin and Clindamycin*, 288 *N. ENGL. J. MED.* 1219 (1973).

157. *Id.*

however, are cases arising not in the criminal field, but in tort. These, it is expected,<sup>158</sup> will arise more frequently as the new developments in fetal research and technology filter down to the individual level.

In many ways, the new knowledge is already affecting individuals, both beneficially and adversely. When the effect is beneficial, we rarely hear about it. When the effect is adverse, the case winds up in the courts. The cases so far have fallen into two categories. The first is brought by the woman who gave birth to the child and she is generally granted relief. The second is where the case is brought by the child and he is generally denied relief. The reasons for this inconsistency in the law will be pointed out in the following discussion.

Cases falling into the first category include an action by the parents of a deformed child against the mother's doctor for his failure to diagnose rubella during the course of the pregnancy.<sup>159</sup> The child was born with defects of the brain, speech, sight, hearing, kidneys, and the urinary tract, among others. In their malpractice suit, the parents claimed damages for their physical, emotional, and financial suffering.<sup>160</sup> The Texas Supreme Court said their claim stated a cause of action.<sup>161</sup> A New York court has held that a malpractice claim against a doctor for not diagnosing a pregnancy in time for an abortion states a cause of action.<sup>162</sup> There was a strong dissent in the case based on the premise that "parents should not be able to enjoy the pleasure and comfort of their child and also seek compensation for its birth."<sup>163</sup> A Michigan court has ruled that a woman has a cause of action against a pharmacist for mistakenly filling a prescription for the contraceptive Norinyl with a different drug, Nardil.<sup>164</sup> The woman was suing for medical expenses attendant upon birth, the pain and suffering incident to childbearing, plus the cost of raising the child.<sup>165</sup> Finally, an Illinois court concluded that when a wife's doctor orally agreed to sterilize her husband so as to prevent procreation, the operation was performed and they resumed sexual relations

158. Cases in tort have been anticipated in England (*Editorial*, 41 MEDICO-LEGAL J. 45, 1973) and in this country (Warshafsky, *Mental Retardation Can Be An Avoidable Affliction*, 10 TRIAL 30, May/June, 1974). The National Commission for the Protection of Human Subjects is also concerned about how to compensate individuals injured as a consequence of their participation as research subjects. "Compensation not only for injury from research but for participation in research as a normal volunteer or in a therapeutic situation will be part of later Commission deliberations." *The Commission Report: Deliberations and Conclusions*, 5 HASTINGS CENTER REPORT 44 (June, 1975).

159. *Jacobs v. Theimer*, — Tex. —, 519 S.W.2d 846 (1975).

160. *Id.*, 519 S.W.2d 846, 848.

161. *Id.*, 519 S.W.2d 846, 850.

162. *Ziemba v. Sternberg*, 45 A.D.2d 230, 357 N.Y.S.2d 265 (1974).

163. *Id.* For a contrary result based on the reasoning of the dissent in the principal case, see *Rieck v. Medical Protective Company of Ft. Wayne, Ind.*, 64 Wis. 2d 514, 219 N.W.2d 242 (1974).

164. *Troppi v. Scarf*, 31 Mich. App. 240, 187 N.W.2d 511 (1971). See also, Omenn paper, *supra* note 5, at 15.

165. The case was subsequently settled. See Omenn paper, *supra* note 5, at 16.

and subsequently gave birth to a third retarded child, the complaint stated a cause of action in contract.<sup>166</sup>

These cases are not startling, they are not even new.<sup>167</sup> When a physician or pharmacist is negligent or when a doctor has breached an oral contract, it is logical to assume that the complaint states a cause of action. What is of interest and what is startling, is when, based upon virtually the same set of facts, a court will allow the woman who gave birth to the unwanted or defective child to recover, but it will not allow the child to recover for wrongful birth.<sup>168</sup> This leads to the second category of cases which are few in number but which have a very interesting history.

### *Wrongful Birth*

In 1963 the Illinois Appellate Court labored over its decision in *Zepeda v. Zepeda*.<sup>169</sup> The facts are only tangentially pertinent to our discussion: an illegitimate son was suing his putative father for fraudulently inducing his mother to have sexual relations upon the promise of marriage. The father was already married. The child sued for damages for deprivation of a normal homelife, deprivation of rights of inheritance, and for having to suffer the stigma of being born a bastard.<sup>170</sup> The court denied the plaintiff relief because "recognition of the plaintiff's claim means creation of a new tort: a cause of action for wrongful life."<sup>171</sup> The court was not pleased with the result it reached,<sup>172</sup> but finally concluded that this new cause of action could not be created judicially but rather the "representatives of the people" must act.<sup>173</sup> The most interesting sections of the court's opinion are the forecasts of the very problems being grappled with today. The court, in effect, predicted the thalidomide disaster,<sup>174</sup> genetic malformation resulting from radiation,<sup>175</sup> sperm banking,<sup>176</sup> and cloning.<sup>177</sup> In each hypothetical the court concluded

166. *Doerr v. Villate*, 74 Ill. App. 2d 332, 220 N.E.2d 767 (1966).

167. *See id.*, which was decided 9 years ago.

168. The courts have struggled with the concept of wrongful birth (or wrongful life) since the landmark case of *Zepeda v. Zepeda*, 41 Ill. App. 2d 240, 190 N.E.2d 849, (1963), *cert. denied*, 379 U.S. 945. *See also*, *Williams v. State*, 18 N.Y.2d 481, 223 N.E.2d 343 (1966); *Coleman v. Garrison*, 317 A.2d 757 (Del. Sup. Ct., 1974); and *Aronoff v. Snider*, 292 So. 2d 418 (Fla. Dist. Ct. of App., 1974).

169. 41 Ill. App. 2d 240, 190 N.E.2d 849 (1963), *cert. denied*, 379 U.S. 945 (1964).

170. *Id.* at 246.

171. *Id.* at 259.

172. (It may be inconsistent to say, as we do, that the plaintiff has been injured by a tortious act and then to question, as we do, his right to maintain an action to recover for this act. This is done deliberately, however, because on the one hand, we believe that the elements of a willful tort are presented by the allegations of the complaint and, on the other hand, we approach with restraint the creation, by judicial sanction, of the new action required by the complaint.

*Id.*

173. *Id.* Other scholars have called for legislative action. *See, e.g.*, *Tedeschi, On Tort Liability for "Wrongful Life"*, 1 ISRAEL L. REV. 513, 532 (1966).

174. 41 Ill. App. 2d 240, 250.

175. *Id.* at 251.

176. *Id.* at 261.

177. *Id.* at 262.

that a cause of action for wrongful life should lie. Unfortunately, the "representatives of the people" have not yet legislated in the area.

Nonetheless, *Zepeda* had clearly set the stage for affirmative activity in this area. Three years later, the New York courts had the opportunity to take *Zepeda* one step further but refused to do so.<sup>178</sup> In *Williams v. State*<sup>179</sup> an illegitimate daughter brought suit against the state for deprivation of property rights, deprivation of a normal childhood, and deprivation of proper parental care, support and rearing, in addition to having to bear the stigma of illegitimacy.<sup>180</sup> The child's mother was a patient in a state mental institution when she was raped by another inmate. The woman became pregnant and gave birth to the plaintiff. The court gave short shrift to the matter and dismissed the complaint when it said: "Being born under one set of circumstances rather than another or to one pair of parents rather than another is not a suable wrong that is cognizable in court."<sup>181</sup> The concurring opinion was based upon the question of damages.

Damages are awarded in tort cases on the basis of a comparison between the position the plaintiff would have been in, had the defendant not committed the acts causing the injury, and the position in which the plaintiff presently finds herself. The damages sought by the plaintiff in the case at bar involve a determination as to whether nonexistence or nonlife is preferable to life as an illegitimate with all the hardship attendant thereon. It is impossible to make that choice.<sup>182</sup>

The courts, by construing the child's cause of action to be, whether it is better to never have been born at all than to have been born in the condition in which the plaintiff finds himself, have effectively cut off all avenues of relief that might be available to him. This construction must be overcome by legislation enacted by the "representatives of the people" if we are to achieve true accountability in science. One case, *Mellis v. Chicago Wesley Memorial Hospital*<sup>183</sup> decided last June in the trial court of Cook County vividly illustrates this need. The facts of the *Mellis* case are of particular interest to our discussion because they remove the cause of action for wrongful life from the area of illegitimate children and place it in its new environment: a child harmed because of the confrontation of the individual versus the scientific community.

A husband went to defendant hospital for a routine check-up. A doctor in the hospital discovered he had thalassemia minor. In other words, he was a

178. *Williams v. State*, 18 N.Y.2d 481, 223 N.E.2d 343 (1966).

179. *Id.*

180. *Id.*

181. *Id.* at 482.

182. *Id.* at 483. The *Zepeda* and *Williams* decisions spawned a plethora of law review articles. See, e.g., Tedeschi, *On Tort Liability for "Wrongful Life"*, 1 ISRAEL L. REV. 513 (1966); Note, 18 STAN. L. REV. 530 (1966); Plascowe, *On Action for "Wrongful Life"*, 38 N.Y.U.L. REV. 1078 (1963); and Gordon, *The Unborn Plaintiff*, 63 MICH. L. REV. 579 (1964-65).

183. No. 70L-15177 (Cir. Ct. Cook Cty., Ill. June 18, 1974).

carrier for this deadly disease.<sup>184</sup> As a precaution, the hospital requested that his wife come in for a test also, to determine whether she, too, was a carrier. The hospital found she wasn't. The wife became pregnant and delivered a baby with thalassemia major. The wife was thalassemia minor carrier also, which the hospital failed to detect. The baby was a homozygous affected offspring, of which there was 25 percent probability.<sup>185</sup> The child brought suit against the hospital for wrongful birth. The case was dismissed for failure to state a cause of action. The injustice of this decision becomes more apparent when it is noted that the hospital could have prevented the child's condition in two ways: first, by testing the mother in a non-negligent manner so as to discover her true carrier status, and second, knowing the possibility of a thalassemia major child being born to the couple, the hospital could have tested the child *in utero* with the amniocopy procedure earlier.<sup>186</sup>

Clearly, the new technology will result in more fact patterns similar to the *Mellis* case. These children must not be turned away from the courtroom door empty-handed on the shallow basis that the courts cannot judicially answer whether it would have been better not to have been born at all than to have been born in the condition in which the plaintiff finds himself. The problem must be treated. If the legislatures refuse to act, then the courts must overcome this "logico-legal" difficulty.<sup>187</sup> One author has suggested a way in which this can be done.<sup>188</sup> He concluded that the courts should not compare the child to nothing, but to something. In this line of reasoning, he suggests the following words be put into the mouth of the infant plaintiff:

Had you done your job correctly, it is true I would not be your accuser today. I would have had no recourse against anybody because when I died, I was not a person or at least, I was not legally recognized as such.

But your wrongdoing allowed me to become a person but not like other persons. I cannot see, I cannot speak, I cannot walk and I will never possess the intellect that would allow me to develop into a mature human being. I will never enjoy those things which God intended all human beings to enjoy.

I asked not to be born. I could not so ask and the law gave me no such right. But the law says I have a right to be born with my faculties unimpaired and were it not for your negligence, I would not have been born the way I am. Don't compare me the way I am with the way I never was.

Compare me the way I am with the way other normal and healthy human beings are since you cannot compare me with nothing but only with something.

184. See *supra* note 23 and accompanying text.

185. Omenn paper, *supra* note 5, at 9.

186. See *supra* notes 22 through 26 and accompanying text.

187. *Williams v. State*, 18 N.Y.2d 481, 223 N.E.2d 343 (1966), Keating, J. concurring, quoting *Tedeschi, On Tort Liability for "Wrongful Life"*, 1 ISRAEL L. REV. 513 (1966).

188. Dachs, *Liability for Wrongful Harm to the Unborn — Past, Present & Future*, 166 N.Y.L.J. 1 (Aug. 2-4, 1971).



Since you cannot give me that which others have when they are born, I ask only that, in accordance with the laws of all civilized societies, you make my life easier by giving me in like measure the funds necessary to compensate me for my hurt and to obtain the assistance that I will require for the rest of my life.<sup>189</sup>

Thus, the courts can act or the legislatures can act. In any event, wrongful life must become actionable if science is to become truly accountable.

#### CONCLUSION

This paper has indicated the present posture of the fetal research controversy. It has attempted to show, through a review of the latest research endeavors in the field, that fetal research should not be proscribed. It has also shown that the scientific community and the medical profession have the built-in, self-regulating mechanisms sufficient to not only handle the controversy themselves, but to protect the integrity of the research subject as well. This paper advocates returning the research opportunities to that community and that profession.

On the other hand, it has indicated two major areas where legislation is badly needed: regulation of semen banks and a statutory cause of action for wrongful life. The legislative response to the fetal research controversy should thus be three-fold: return the research opportunities to the scientific community, legislate and regulate in the area of semen banking, and enact a statutory cause of action for wrongful life. If these three demands are met, the legislatures will thereby assure future children a chance to benefit from the new knowledge, assume responsibility for protecting the many infertile couples now at the mercy of the semen banks, and acknowledge the notion that true public accountability of science is meaningless unless the individual harmed by scientific advances is given his day in court.

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189. *Id.* at 4.