THE FIRST INTERNATIONAL CONFERENCE ON PHILOSOPHICAL ETHICS IN REPRODUCTIVE MEDICINE AND CHALLENGING ISSUES IN BIOETHICS, INTERNATIONAL SEMINAR OF THE FONDAZIONE INTERNATIONALE PREMIO E. BALZAN–"PREMIO"

CONFERENCE REPORT THE FIRST INTERNATIONAL CONFERENCE ON PHILOSOPHICAL ETHICS IN REPRODUCTIVE MEDICINE Leeds, England, April 18–22,1988 and CHALLENGING ISSUES IN BIOETHICS, INTERNATIONAL SEMINAR OF THE FONDAZIONE INTERNATIONALE PREMIO E. BALZAN– "PREMIO" Venice, Italy, May 12–13, 1988.

The First International Conference on Philosophical Ethics in Reproductive Medicine in Leeds was presented as a first attempt at an open, international, public forum for doctors, scientists, social scientists, philosophers, ethicists, theologians, policy makers, lawyers, politicians and anyone else interested in discussing ethical issues surrounding reproductive medicine.'

Initiated by Professor Richard Lilford of the Department of Obstetrics and Gynaecology at St. James University Hospital, the meeting started off on a pro-technology footing. Both introductory talks came from well-known advocates of the new reproductive and genetic technologies, The Reverand Gordon Dunstan of Exeter speaking on "The Moral Status of the Human Embryo," followed by US policy commentator and former developmental biologist Clifford Grobstein on "Genetic Manipulation and Experimentation." Dunstan's arguments followed a long line of Western intellectual thought on the status of the embryo from Aristotle through the Middle Ages to modern embryology and genetics. Grobstein defended the social use of gene manipulation, IVF (*in vitro* fertilisation), and freezing eggs and embryos to direct the course of human evolution. Grobstein seriously considered the use of these methods for, among other things, extraterrestrial colonization. And indeed it was difficult for participants with wider concerns, such as the risks to women of drug regimens and techniques, or the social implications of the importance being placed on genetic relationship, or primary health care, to have these concerns taken up and discussed on the same scale.

But looking back at the conference, I see the rumblings of critical opinion, although for the most part these are not overtly informed by feminist concerns. Many nonclinical participants were not as enamoured with the hyper-scientific approach, and its advocates are getting nervous about it. A few weeks after the Leeds conference, a newspaper headline bore me out. Reporting on the international[2] seminar Challenging Issues in Bioethics in Venice, the headline read: "Scientists warn of 'mob rule'" (McKie, 1988).

This second international meeting was a more formidable grouping, sponsored by the Italian-Swiss Balzan Foundation.[3] According to Linda Bullard of the Gene Ethics Network in Berlin, it was a slick public relations display of the best-known names in the area invited to talk about genetic engineering, reproductive engineering, euthanasia and randomized clinical trials.

Speakers included IVF pioneer Professor Robert Edwards; Baroness Mary Warnock, chair of the British Committee of Inquiry on Human Fertilisation and Embryology; and one of the most well known antagonists of biotechnology, Jeremy Rifkin, who stressed the need to look at the costs and risks of genetic engineering. His organisation, Foundation on Economic Trends in the USA, have taken companies and the US government to court to stop genetic engineering projects. With environmental activists, they were instrumental in delaying the first release of a genetically engineered organism into the open environment in the USA. In Venice, Rifkin stated his aim of creating coalitions of pressure groups to block reproductive and genetic engineering research.

Edwards warned of "mob rule" by public

pressure groups bent on stopping scientists, and Warnock said "We face the return of a new dark age in which rhetoric will take the place of rational thought." Another scientist, Professor Michael Baum of King's College London, summarized opposition to the new technologies as "dogmatism" and "absolutism" (McKie, 1988). It is interesting that up until recently, scientists in England advocating reproductive engineering have repeatedly cited favourable public opinion as a reason they should be allowed to continue with their medical/scientific work. But when they perceive public opinion is not on their side, it is described as irrational and dogmatic.

The Leeds conference was perhaps a shadow of what it set out to be. It did not attract the big IVF names, and although every British MP (Member of Parliament) was invited, none came. It was not so much about the ethics of reproductive medicine as about the ethics of high-tech developments in reproductive medicine such as IVF, human embryo research, using fetal tissue for transplants, gene manipulation, freezing embryos, surrogacy. Talks and discussion centred on or inevitably turned back to those classic, familiar terms of the mainstream debate: the "status of the embryo/fetus" and the fascinating status of science. Social and legal issues were made to fit into that framework, including the perceived tension between fetal and women's rights. Some of the same old concerns of malestream biomedical ethics cropped up, such as fetal viability and abortion, the embryo's "right to life," sterilisation of the handicapped, and social anxiety over lesbians and single women seeking artificial insemination. Similarly, papers from the Balzan seminar round table "New Reproduction: the genetic vs. the social essence of the family" reflected the same preoccupation with embryos/fetuses and the nuclear family.[4] These concerns can be summarized in the following ways:

1. How is motherhood and the family effected?

The main topics of day two of the Leeds conference were mainstream societal and religious concerns surrounding artificial reproduction techniques. It became one of many contexts for anti-abortion and profamily concerns to be voiced.

Surrogacy was discussed here, and by several male speakers throughout the conference, each proposing his own labels for the women involved. There was "weak" and "strong" surrogacy, the former meaning a surrogacy arrangement based on a woman's voluntarily giving up her child, and the latter meaning a system where the commissioning parties are automatically made the legal parents. There was "genetic" surrogacy and "gestatory" surrogacy, depending on whether the woman is inseminated or whether she receives an embryo from somewhere else. There was "partial surrogacy" (the donor embryo variety) and "total surrogacy." More critical, Dr. Robert Snowden, a psychologist from the Institute of Population Studies in Exeter, proposed turning the usual terminology around. He would like to use the term "real mother" for the woman who bears the child and "surrogate mother" for the woman who would become the mother. He was worried about heterosexual family relations.

By contrast, Ruth Chadwick of the Department of Philosophy at University College, Cardiff, Wales, compared the "body-as-property" line of reasoning to Kant's belief that people have duties toward their own bodies since a human being is the embodiment of the person. She criticized the individualistic and market-oriented context in which women might feel obliged to sell our eggs and reproductive capacities to make a living. She described and rejected a concept of "collective ownership" of bodies by which surrogacy becomes a moral imperative for the collective of women.

A session on withholding neonatal care prompted questions of infanticide, the best interests of the child, quality of life, and effects on the family. Outlining the history of the incubator, Professor Alexander Campbell of Aberdeen said that increasing capabilities in neonatal technology can allow premature babies weighing 500 grams to be kept alive, whereas years ago babies weighing less than 1000 grams were considered nonviable. He boldly offered that neonatal and perinatal technology are "truly the temples of high technology medicine," concluding that limits must be put on administering neonatal care or else it could become child abuse in cases where treatment causes more suffering than good.

2. When does an embryo become and embryo?

Peter Singer, Director of the Centre for Human Bioethics at the University of Monash in Australia, spoke on "IVF and Australian Law" in Leeds. He began with a list of Australian "firsts" in the IVF

field, to show their standing at the "forefront of scientific achievement." Australian IVF teams pioneered hormone stimulation of women to produce multiple eggs, and effected the first births using a frozen embryo and a frozen egg. There are no federal laws on IVF, and Singer noted that it is not constitutionally clear if the federal government can legislate in this area. Hence, he concentrated on the situation in the state of Victoria and its 1984 Infertility Medical Procedures Act, the first IVF law in the world. It states that eligibility must be restricted to married women; that as a condition for entry into an IVF programme the couple must have been in treatment for 12 months already or the fertility problem must be proven unresponsive to other treatments; qualified counselling must be given; and the controversial Section 6.5 prohibits the creation of embryos for anything but transfer to a woman.

Section 6.5 is a thorn in the sides of IVF practitioners who see the need for research on human embryos, and Singer expressed that he himself supports IVF methods only if research were allowed to continue so that the low success rates could be improved. The major question prompted by Section 6.5 is "when does an embryo come into existence?". One conclusion is that an embryo is not present until the genetic material intermingles in the fertilized egg (at the earlier stage of egg and sperm fusion, the chromosomes of each exist separately from each other in discrete nuclei).

The question "when does an embryo become an embryo?" has been a burning one in Britain and other countries for trying to accommodate the status of the embryo to the pursuit of scientific research. In Britain, the term "pre-embryo" was coined in 1985 by the Voluntary Licensing Authority (VLA) to mean the embryo up to 14 days after fertilisation outside a woman's body. The VLA was set up to oversee IVF and embryo research *after* this 14-day limit was recommended on embryo research in the Warnock Report, the British government inquiry on the issues. At the conference, many British speakers defending embryo research used the term pre-embryo, but most other speakers and discussants did not. (Singer's opinion at the Balzan meeting was that the 14 day upper time limit is too conservative, and that it is ethical to experiment with embryos up to the time they would feel pain.)

3. Declaring women's rights, or bolstering medical science?

Women's rights, choice and autonomy were not central concerns of either conference, but were sometimes mentioned to defend the interests of medical scientists to pursue certain lines of research and therapy.

In Leeds, discussions of abortion, including pro-abortion arguments, were sounded, but not as concerns of women. They were juxtaposed with discussions about using embryos and fetuses for medical/scientific experimentation and therapies. One of these panels included Professor Fritz Beller of the University Women's Clinic in Munster, FRG. Beller, a controversial figure in the Federal Republic, argued in favour of using anencephalic babies (babies born without brains) as organ donors on the assumption that "anencephaly is equivalent to braindeath." His team in Munster has already used three anencephalic fetuses as "organ donors" for renal transplantation, after removing them from the women by induction of labour after the 30th week gestation. Four to six hours after delivery, the kidneys were removed by transplantation specialists and transplanted into recipients selected by the Eurotransplant computer. He called the anencephalic "a special experiment of nature," and suggested that it is acceptable that women be asked to continue pregnancies for such organ donation. Soren Holm of the Institute of Neurophysiology in Copenhagen similarly suggested that the mother has a right to decide what to do with the fetus whether it is aborted or miscarried – that is, a woman has a right to donate her fetus to medical science.

In a thoughtful reply to these arguments, a woman doctor in the audience showed two slides of anencephalic babies since people sometimes did not know how to imagine them. One showed the mother cuddling her newborn, who certainly would shortly die.

The use of fetuses for transplants was a timely topic in Leeds, as two days before the conference convened, Britain's first operations using fetal cells to treat Parkinson's disease took place at the Midlands Centre for Neurosurgery by Professor Edward Hitchcock. Dr. Richard West, chair of the ethical committee which approved the transplants, made an appearance to explain the decision. Dr. West noted that 1 of the 7 members of the ethics committee was a lay (nonmedical) person, and that

none of them was particularly schooled in ethics. They based their decision on consensus, he said, and added that since the operation was reported, several women called to offer their aborted fetuses for use in such treatment. Dr. Pamela Sims, a British gynaecologist who is "pro-life" but also was one of the few speakers who voiced worries about the risks to women of certain medical procedures, asked if the woman must undergo a hysterotomy abortion (a Caesarean-section type operation) to keep the fetus intact. West replied no. (Other doctors and researchers disagree here.) Raanon Gillon, editor of *Journal of Medical Ethics*, in summarizing the ethical issues involved, offered that the woman's autonomy is respected in that her consent is respected, although he added that this may not be sufficient. However, he summarized, "Clearly, the problems all arise with respect to the fetus."

Jean Robinson, an invited speaker and lay member of the General Medical Council[5], made an impassioned comment to Dr. West from the floor. As a lay member on a medical body, she said it was likely that a single lay member on an ethics committee would get sucked into the medical-science ethos and not be able to voice her or his opinions. Criticizing the decision to allow tissue from aborted fetuses to be used for medical procedures, she asked West where the informed consent form came from, and what it said. He did not know. Robinson replied that this was totally unacceptable, that women in Britain had never before been asked to sign such forms, and she warned that fetal tissue was potentially big, big business, and that this would effect the context in which women were set up to make decisions. She was the first person to strongly criticize the medical specialists involved, and her presence shifted the atmosphere of the conference.

In her talk "Pregnant Guinea Pigs: The Consumer Perspective," Robinson cited the routine use of ultrasound on healthy pregnant women without adequate knowledge of long-term risks. She made the comparison with DES, the drug given to pregnant women in the 1950s and 60s to prevent miscarriage, which was later proved ineffective. Now the daughters of women who were given DES are at risk of developing a rare form of vaginal cancer, and other health problems are being associated with their sons and daughters, including fertility problems. Robinson voiced her reservations about the ethos of reproductive research, where the interests and power of researchers and manufacturers looms over those of consumers. She noted problems with a simple acceptance of "consent to research" and the differences in treating women and men in similar medical contexts. Men, she said, were given information by doctors, while women were given assurance. As a result of a study of pregnant women who were asked to take part in medical research, she learned that most of them were asked for consent to a new procedure or project while they are in labour, after their husbands or partners were asked to leave the delivery room. She suggested that consent for research should be accompanied by a delay – for instance, 24 hours – to give the person time to think over the decision, which would be especially important for pregnant women.

Iain Chalmers of the National Perinatal Epidemiology Unit supported Robinson, and at one juncture in his talk commented, "A belief in the scientific method is a belief . . . not a certainty." He made several blunt criticisms of medical professionals including that publication bias – publishing studies which show positive results rather than null ones – is inadequately recognized in the profession. He also looked at the DES situation and rhetorically asked if the interests of pregnant women were served by those acting in "good faith" over DES. He briefly discussed the Medical Research Council's clinical trials of chorionic villi sampling, questioning the level of informed consent and the context in which it was developed, and quoting a Hungarian doctor who introduced the method asking others not to dwell on the "complications" (dangers) of the procedure. Professor Lilford commented that doctors choose treatment, to a large extent, on "hunches" that it is good, not on scientific fact.

A central concern of Robinson and Chalmers was the need for a better approach to medical research. In particular, they both argued the need for randomized clinical trials to assess the efficacy and risks of treatments before they became accepted medical practice. Taking a diametrically opposed view was Denis Hawkins, editor of *Journal of Obstetrics and Gynaecology.* He criticized putting such faith in randomized trials, and was bitterly critical of Robinson, attacking her personally. But neither did he believe that medical

research was a priestly mission. Commenting on informed consent he noted that researchers conduct studies to write papers, not to help women to get the best medical management. I suppose his view could be summarized in two of his statements. He believes that the longer a procedure has been around, the less one needs a randomized trial; and that the worth of some methods are self-evident – like epidurals.

Informed consent was the main topic of the last day of the conference. Participants had frequently brought up the subject the previous four days, but a discussion was never pursued at those times. Another problem with the informed consent discussion was that speakers continually used gender neutral language in describing the relationship between doctors and subjects (who are mostly women in the contexts discussed here).

Professor Sam Gorovitz from Syracuse, New York, related both humorous and sad stories of the lack of communication between doctor and patient as an example of the fundamental problem with presuming that informed consent erases ethical problems. Simon Lee, lecturer in law at King's College, London, outlined legal problems and considerations with informed consent. He cited as of great importance the Sidoway case in England, where a mentally handicapped girl was sterilised without her consent. He showed how there is no satisfactory legal theory of how judges make decisions in consent cases in Britain, and offered that forthcoming debates over Warnock Report considerations will raise the issue of who, if anyone, can consent.

4. Who is pressuring whom?

Financial support for the Leeds conference was provided by several pharmaceutical companies and a private infertility clinic, Allerton Medicare PLC which offers IVF and GIFT (Gamete Intrafallopian Transfer) services. The pharmaceutical companies, all of whom are listed in the International Biotechnology Directory 1985 (Coombs, 1985), were: Hoechst UK Ltd; Roussel Laboratories Ltd; Serono Laboratories UK Ltd; Upjohn Ltd.; and Wyeth Laboratories, "World leaders in Oral Contraceptives" who took the opportunity to advertise their new contraceptive pill, Minulet.[6]

Serono's publicity stall carried literature and posters advertising their products, and mid-way in the conference, realizing that few participants visited the display, they put together a short quiz whose answers could be found at the stall. For example, one question asked "On which day of the cycle would you commence REHIBIN (cyclofenil) treatment?". The first correct entry selected won, appropriately, a copy of the book *The Status of the Human Embryo* by Gordon Dunstan.

Twice from the floor, a woman representing the birth lobby National Childbirth Trust voiced her frustration over the high-tech and academic emphasis of the conference to say that a lot more research on less glamorous medical matters was needed, and that such debates should be broadened to include more members of the public. Jean Robinson stressed that the money for bio-medical research should not be coming from industries whose interests are served by more drugs and more high-tech methods. Going back to Edwards' and Warnock's comments at the Balzan conference, the question arises, who *really* is the "mob?"

In my opinion, at this point in the history of the debate on human applications of reproductive and genetic engineering, the persistent ignoring of feminist arguments about IVF, embryo research, using fetal tissue for transplants, and other applications is nothing less than bad faith. Many IVF practitioners and ethicists, for instance Peter Singer, are familiar with feminist criticisms which stem from the recognition that all the methods and the research requires medical use of women's bodies and social control of women's reproduction (for example, redefining motherhood in the context of egg donation or surrogacy). Failure to address the ethics of using women for biomedical science, while continuing to portray opposition to the technologies as religious fundamentalism or the sentiment of people who believe in the embryo's right to life, is misleading and obscures the role of women as the primary experimental subjects of biomedical research. It obscures the physical and emotional burdens reproductive technologies place on women: the risks of hormonal drugs and invasive procedures, the growing reasons for contemplating genetic screening, embryo manipulation, pregnancy intervention technology, the use of eggs and embryos for medical/science, and more. These meetings demonstrated, however, that ethical questions and issues antagonistic to the view that "scientists and doctors know best" are beginning to surface in meetings where they have

not been placed on the formal agenda.

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ENDNOTES

1. But as Professor Richard Lilford pointed out in the opening ceremony, although many women were at tending this conference, there would be a "preponderance of old men" speaking from the podium. To defend the situation, he humorously quoted Aristotle: if you want to know about something, go ask an old man.

2. Both conferences claimed to be international, but actually represent three continents, North America, Western Europe and Australia.

3. The International Balzan Foundation was instituted by Angela Lina Balzan in honour of her father, with the large estate she inherited from him. The foundation aims to encourage culture and the sciences.

4. Mary Warnock defined the "Artificial Family" as "where children are brought up by people who are socially and legally deemed to be their parents but where one or both are genetically unrelated to the children." (Quoted from her paper "What do we want of the Family?" distributed at the conference.)

5. The General Medical Council governs medical ethics in Britain. All doctors must by law submit to its jurisdiction.

6. Minulet is also marketed as Femodene by the pharmaceutical company Shering. In the last weekend of May 1988, the first British death associated with Femodene was reported. A nineteen year old woman, Dawn Watson, died four months after starting the contraceptive regimen. A Home Office pathologist said that the bloodclot caused by the drug formed in her leg and travelled to her heart and killed her (Deer, 1988).

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