# Ethics & Market Market

# A Christian Perspective on Issues in Bioethics

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# COMMENT

### From the Editor

## Human Fertilisation and Embryology

The UK debate on embryo rights and research has reached the end of a chapter with the passage through Parliament of the Human Fertilisation and Embryology Act. From the perspective of this journal and many of its readers, the Act represents a disaster for the moral health of the nation and the welfare of many of its people: human embryos who will perish because they are 'spare' to the purposes of those who have power over them, many adults who believe they can gain advantage from the availability of IVF-related technology, children yet to be born whose origins lie in this instrumental use of human beings, and - above all - those human beings in the early embryonic stage of their human story whose lives are now legally forfeit to those who have power over them, and whose vivisection may now be licensed by the Human Fertilisation and Embryology Authority. The net liberalisation of the law on abortion which came about as a result of attempted amendment of the Act was a spectacular own-goal for the pro-life movement, but its significance is still overshadowed by the bulk of the Act and its long-term implications.

We have waited long for this legislation, and with reason. The medical-scientific establishment was traumatised by the public and political response to Warnock, and set about a massive campaign of persuasion to ensure that when the crucial vote came it would be in the bag. It is galling that this campaign was largely sustained by public funds (it would be a worthwhile exercise for a benefactor to commission a major firm of accountants to do a tally). Its tactics covered everything from the coinage of the term 'pre-embryo' to the establishment of the 'Voluntary Licensing Authority' (deftly retitled 'Interim' when the prospect of a statutory authority came over the horizon) to the lengthy post-Warnock delay which, as each year passed, gave the pro-embryo research lobby further opportunity to overturn the arithmetic of the Commons votes for Enoch Powell's Unborn Children (Protection) Bill. In saying that we do not suggest that all, or many, of those who have argued the case for the position enshrined now in legislation have been disingenuous or underhand, though some undoubtedly have. The coinage of 'pre-embryo' was ablot on the integrity of the scientific community (resisted to the end by government draftsmen, to their honour). The same may be said for the spread of disinformation about the miraculous properties of deleterious embryo research (which the public and many politicians now believe will provide cures for all sorts of nasty conditions).

Ethicists and lobbyists and the rest of us have much to learn from what happened, and the post mortems have been taking place.We largely lacked media sympathy, which is almost essential in a longrunning debate like this one. The superior research and information resources of the establishment was another major factor: the pro-life movement, which spearheaded the political campaign, has put far too little of its resources into the kind of serious research which alone enables serious arguments to be won, and there is a lesson there which must be learned for the future as the issues become more complex and their significance ever darker. Rutherford House's modest development of a Centre for Bioethics is one little response here. What we need to remember is the growing significance, not just of the 'medical-scientific establishment' as we have – perhaps unfairly – called it, but of the 'bioethics industry': the rapid growth of academic engagement in the production of apologia for what the scientists can, and therefore wish to, do. Of course there is bioethics and bioethics; but the *function* of much of what passes for 'ethics' is not to act as a check, judging new proposals according to tested ethical criteria, but actually to construct arguments to defend new techniques. Large charitable foundations (some of them funded by profits from the drug companies) are increasingly involved in sponsoring research in bioethics, and the trend of much of it is disturbingly uncritical of the scientists and their intentions.

We are not Luddites. As Christians who believe in the mandate to subdue the earth we believe in science as an aspect of man's stewardship of creation. Yet science sans stewardship is power without responsibility, as the next chapters of this story are going to make increasingly clear. As we have pointed out before, the crisis of medical science today is the product of the coincidence of two factors: the moral uncertainty of the emergent post-Christian society, and the opportunities offered by a new technology in reproductive medicine and genetics. The logic of this coincidence is that of swift and unpredictable change, and in the coming years we may sense the fear of the roller-coaster without the security at the back of our minds of knowing that the track is safely in place.

Of course, there is good news too. The report of the Council of Europe's Ad Hoc Committee on Bioethics, to which we have referred on an earlier occasion, was of a different character (why was more use not made of this in our debates?). West Germany has taken a different line, in common with several smaller European countries (though the reunion with the DDR raises important questions about German policy in this area). Yet in the UK, the home of test-tube-babyism, the debate has gone against both reason and faith in a frenzy of self-interested consumerism in which we have chosen to consume even our own selves. In whose interests, we must keep asking, can that be?

\*A number of letters have been received on the question of 'Rescue' as a policy in opposition to abortion. We shall carry one or two in a forthcoming issue of the re-vamped *Ethics and Medicine* Forum.

# **CAHBI:** Europe needs a Universal Bioethical System

### Dr Karel Gunning, Holland,

President of the World Federation of Doctors who Respect Human Life

### Summary:

Bioethics must be seen as part of the ethics for the whole (pluralistic) society. Europe needs an OBJECTIVE ethical system, that is a system which is valid and acceptable for the whole community (Europe), but also a UNIVERSAL ethical system, that is a system which is valid for all mankind. This article makes a plea for a bioethical system which is based on the same principles and aimed at the same ideals as the European Convention on Human Rights.

### 1. Ethics and the Council of Europe

CAHBI (*Comité ad hoc sur la bioéthique*), or *Ad Hoc* Committee on Bioethics, is an institution of the Council of Europe. The Statute of the Council of Europe was signed in London on 5 May 1949 by 10 states (Belgium, Denmark, England, France, Ireland, Italy, Luxemburg, Netherlands, Norway, Sweden). Today it comprises 23 member states and two main organs: decisions are made by the Committee of Ministers, consisting of the 23 Foreign Ministers, each of whom holds the chairmanship in turn for a six-month period. Whilst they meet twice a year, their deputies meet each month for about a week. The Committee receives recommendations from the Parliamentary Assembly, which meets three times a year and is composed of 177 members of the 23 parliaments.

One of the first acts of the Council was the institution of the European Convention for the Protection of Human Rights and Fundamental Freedoms, briefly the European Convention. In this Convention the member states engage themselves to the collective enforcement of certain of the Rights stated in the Universal Declaration of Human Rights, proclaimed by the General Assembly of the United Nations on 10 December 1948. By virtue of this Convention the European Court of Human Rights was set up 'to ensure the observance of the engagements undertaken by the contracting parties'. This Convention and the Universal Declaration, of which it is the result, can be regarded as the expression of an ethical system.

Ethics is the teaching which distinguishes between good and evil, the teaching which deals with the question: what ought I to do? An ethics or an ethical system is a coherent system of rules, based on a specific principle and/or aimed at a specific end. Professional ethics, such as medical ethics, is an ethical system which is valid for a specific profession. Thus Hippocratic ethics is a system of medical ethics which is expressed in the so-called Hippocratic Oath. This is one of the oldest ethical systems, as Hippocrates was a Greek doctor who lived four centuries before Christ. Bioethics is a recently coined notion, comprising both medical ethics and the ethics of biomedical rescarch.

There are several ethical systems, some of which are distinguished by a name, which indicates the principle on which the system is based or the end at which it is aimed. An ethics which is based on religious revelation can be called religious ethics. A system aimed at 'the greatest possible happiness for the largest possible number' is called hedonistic. An ethics which takes good as being equal to useful, is utilitarian, and a system which aims at a maximum of health and force is called vitalistic. The essence of an ethics such as is described in the European Convention, however, cannot be expressed by one adjective.

There is a definite distinction between the juridical and the ethical approach to what is good and evil. A lawyer goes by what is written in the law; the ethicist can come to the insight that a certain act is forbidden without any law. A religious ethical system draws its conclusions from a divine order, whilst a system which is aimed at a specific end can tell whether a certain road will lead to that end or not. Ethics in itself does not have a coercing character. A law may support an ethical rule by rendering contravention punishable. By means of the European Convention the contracting parties are obliged to uphold a number of ethical rules. But ethics goes beyond law or treaty. In principle ethics gives the broad outlines of what should be done by gentle persuasion, which comes from an inner logic. But everyone remains responsible for his own acts. This inner logic precedes and is independent of any lawmaking. An ethical rule is valid with or without the support of a law. But in order to make people apply the rule in reality, it can be important to have it laid down in the law.

But ethics goes beyond law or treaty. In principle ethics gives the broad outlines of what should be done by gentle persuasion, which comes from an inner logic. But everyone remains responsible for his own acts. This inner logic precedes and is independent of any lawmaking.

For an institution such as the Council of Europe it is important to adopt an objective ethical system, that is a system which is valid and acceptable for the whole community (in this case Europe), but also a universal ethical system, that is a system which is valid for all mankind. In the pluralistic society of Europe we find not only followers of different religions but also non-religious groups. An ethics which is based on a specific religion, such as Christian ethics, cannot be regarded as binding for those who do not adhere to this religion. That is one reason why such an ethics may be called subjective.

It then is often tacitly assumed that an ethics which is not based on a religious concept should be objective. It is questionable however if this is fair: is the inviolability of man solely based on a religious concept? And can we really say that an ethics which is not based on religion is objective? Does happiness and usefulness for one group not often mean suffering and harm for the weakest? And does the emphasis on health and force not mean that the ill and handicapped will soon lose their right to exist? If objective ethics is a system which is valid for the whole community and subjective ethics is a system which only applies to one group, then the non-religious ethical systems just mentioned are clearly just as subjective as religious ethics. But the objective-subjectiveantithesis has another significance for our discussion as well. Our science has advanced quite rapidly since the day we decided to demand objective proof for any statement or theory (the so-called scientific method). Objective in this sense means that everyone should be able to verify the truth of the statement by means of his physical senses. But our physical senses are only sensitive to physical stimuli. With our scientific method we therefore can only discover a reality composed of physical objects, which we usually call matter. Non-physical substances such as the soul and religious revelation cannot be discovered by the scientific method alone. Neither the existence nor the non-existence of a nonphysical world can be demonstrated by this method.

This means that any really objective statement should consider two possibilities: 1. that matter alone exists, an assumption which is usually called materialism; and 2. that besides matter there is also a non-physical world, usually called the spiritual reality. This second assumption I will refer to as realism. So any scientific conclusion should always consider these two possibilities. There should be one conclusion reached from the materialistic assumption and one conclusion reached from the realistic point of view. This is certainly true, when an ethical conclusion is based on a scientific fact which can be differently interpreted when seen from either the materialistic or the realistic angle. We must realize that both conclusions are equally objective or equally subjective, as the objective scientific method as such is not able to answer which of the two is the right one. Of course in many cases the two conclusions are the same, but then again we ought to say that the conclusion is valid from both the materialistic and the realistic point of view.

We are all members of the human family. If harmful experiments on humans are not allowed, then, seen from both the materialistic and the realistic point of view, research on living human embryos should not be allowed either.

Let us take as an example the argument that research on living embryos should be allowed, because the embryo does not have a soul. Here realism and materialism must disagree, as the soul is a non-physical reality. Having no weight, no volume, no location within the body where it can be said to be present, being invisible, etcetera, materialism must come to the conclusion that the soul does not exist. But if this is true, then no human can ever be said to have a soul, so there is no difference in this respect between the embryo and the adult person. Both are human beings, belonging to the species man, because they possess the genetic material of man. For the same reason realism too must conclude that the embryo is a human being. But from the realistic point of view being alive is equivalent to having a soul. Soul is the directing principle of a living being. So every man has a soul, including the embryo, as it is a living being from conception onwards. So whether we look at the question from the materialistic or the realistic point of view, the embryo is in the same condition as the adult human being. There is no reason to discriminate. We all are members of the human family. If harmful experiments on humans are not allowed, then, seen from both the materialistic and the realistic point of view, research on living human embryos should not be allowed either.

### 2. The Declaration of Human Rights

Ethics deals with human behaviour which may be called either bad or good or neutral. But can we say that behaviour in itself is good, or that it is good in order to reach a certain aim?

Let us take as an example the Universal Declaration on Human Rights. I call this Declaration the expression of an objective and universal ethics. As far as I know, this Declaration has been accepted unanimously by the General Assembly of the United Nations. Nobody will suggest that the UN is a purely Christian or a purely Moslem, or a purely communist organization. Apparently both materialists and realists could decide that the ethics expressed in this Declaration agreed with their own ethical principles so that it was valid and acceptable for the whole world.

What is the explanation for this unanimity? I think the answer to this question is found in the Preamble of the Declaration, especially in the first sentence, which reads: 'Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world.' In other words this sentence says: 'Peace, freedom and justice are values which we want to realize in the whole world; if this is our aim, then we must recognize the inherent value and dignity of each member of the human family and we must recognize that all men have equal and inalienable rights, which are described in this Universal Declaration.' If this is the correct interpretation of the first sentence of the Preamble, then we can say that the amazing unanimity in the UN's General Assembly has been reached because all member nations agreed on a common purpose for humanity: to reach a free, just and peaceful world community, and that, to reach that kind of world, we must accept the human rights as described in the Universal Declaration.

So the Universal Declaration is written in order to reach a definite aim: peace, freedom and justice in the whole world. But it is also based on a clearly defined assumption: all members of the human family have an inherent dignity and all men have equal and inalienable rights. And finally it argues that the aim can only be reached if we accept the assumption as the basis of our action.

Suppose we assume that one specific person lacks the dignity necessary to give him these human rights. In that case the dignity of man cannot be called inherent, because inherent dignity means that this dignity is indissolubly connected with the state of being human as such.

Of course we can challenge this argument. Why should we be obliged to accept *this* assumption in order to reach our aim? The Preamble does not offer any explanation. Apparently the authors have considered this conclusion as self-evident. They may have reasoned that justice means equal rights for every human being; that peace means refraining from deliberately harming another human being; and that freedom means being protected against coercion to do things against our will and conviction. All these conditions are made possible if we recognize the inherent dignity and the equal and inalienable rights of all human beings.

Suppose we assume that one specific person lacks the dignity necessary to give him these human rights. In that case the dignity of man cannot be called inherent, because inherent dignity means that this dignity is indissolubly connected with the state of being human as such. If one single person on earth lacks this dignity, then dignity apparently is not a property which is inherent to man. It is all or nothing. If not all members of the human family possess a dignity which is inherent, then this dignity is not inherently present in any member. And if not all men have equal rights then discrimination is already accepted; and if our rights are not inalienable, then they are dependent on the benevolence of the state. On the strength of this argument an ethics which is based on the inherent dignity and the equal and inalienable rights of all men must be called an objective and universal ethics. A community where this ethics is accepted offers the best guarantee for the development and protection of each human being.

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The unanimity in the acceptance of the Universal Declaration has apparently been made possible because agreement was reached on both the final aim it was meant to achieve and the basic principles which must be accepted to reach the aim. The question is now whether the same end can be reached if these principles are rejected. In other words: if an ethical system is proposed which differs from the one expressed in the Universal Declaration, should we ask for an introduction, which states the principles on which it is based and the kind of society which will result if this ethics is accepted? It is at least conceivable that in this way we may reach unanimity as we all choose that ethical system which is aimed at ideals which are acceptable to all of us.

### 3. A bioethical system which agrees with the Universal Declaration

As the Universal Declaration does not force the member nations to uphold the human rights mentioned therein, the Council of Europe in 1950 has instituted the European Convention, in which the contracting parties engage themselves, as the Preamble states to: 'the maintenance and further realisation of...certain of the Human Rights (...stated in the Universal Declaration) and Fundamental Freedoms...which are the foundation of justice and peace in the world....' Thus the European Convention is a further step for the realisation of the ethics expressed in the Universal Declaration.

It therefore seems obvious to assume that a bioethical system which is acceptable to the Council of Europe should be aimed at the same end and be based on the same principles as the Universal Declaration and the European Convention. On the basis of this assumption we will have to work out a bioethics containing the conclusions which are reached when each bioethical problem is considered from the principles of the Universal Declaration.

In the Hippocratic oath the physician swears that he will use his medical knowledge for the benefit of his patient and not for his harm, that he will never deliberately kill a patient, not even if asked by him, and that he shall not perform abortions.

As bioethics includes both medical ethics and the ethics of biomedical research, it seems logical to start with a system of medical ethics which is based on the principles of the Universal Declaration. This system will be identical with Hippocratic ethics. For this ethical system, which was first expressed in the Hippocratic Oath, has been rephrased in modern language in the Declaration of Geneva by the World Medical Association, for the same motives which have lead to the proclamation of the Universal Declaration, that is to prevent the recurrence of killing humans, in the one case by doctors, in the other by the state.

In the Hippocratic Oath the physician swears that he will use his medical knowledge for the benefit of his patient and not for his harm, that he will never deliberately kill a patient, not even if asked by him, and that he shall not perform abortions. In the house of a patient he will not misuse any male or female, bond or free. And he swears to keep silence on what he has come to know about his patient during the treatment.

As during the last World War over a hundred thousand German psychiatric patients had been killed and prisoners had been subjected to very cruel experiments with the cooperation of doctors, the World Medical Association, in September 1948, adopted the Declaration of Geneva, which contains the words: 'I will respect the secrets which are confided to me; I will not permit considerations of religion, nationality, race, party politics or social standing to intervene between my duty and my patient; I will maintain the utmost respect for human life, from the time of conception; even under threat, I will not use my medical knowledge contrary to the laws of humanity.'

The care and respect for the life and privacy of the patient expressed in this ethics are in full agreement with Article 3 of the Universal Declaration, proclaimed in the same year: 'Everyone has the right to life, liberty and security of person.' This ethics also fits with Article 2 of the European Convention: '1. Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law. 2. Deprivation of life shall not be regarded as inflicted in contravention of this Article when it results from the use of force which is no more than absolutely necessary; a.in defence of any person from unlawful violence; b.in order to effect a lawful arrest or to prevent the escape of a person lawfully detained; c.in action lawfully taken for the purpose of quelling a riot or insurrection.' The cases mentioned in this article are exceptions to the rule that no one may be killed intentionally. In none of these cases is the killing itself regarded as good and the value and dignity of those who are killed is not questioned. If, on the contrary, an ethics is accepted, which permits the intentional killing of a patient by a doctor, on certain conditions, then the killing as such must be regarded as good and not-killing will eventually be called bad. It also implies the recognition that in these circumstances the patient's life is no longer valuable, which would mean that value and dignity cannot be regarded as properties which are inherent to being human.

We can, therefore, conclude that Hippocratic ethics is in full harmony with the Universal Declaration and the European Convention, because this ethical system too is based on the inherent dignity and the equal and inalienable rights of everyone, born or unborn, man or woman, bond or free.

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We should add that instead of killing the patient, we doctors should take all the necessary steps to make sure that the patient does not suffer needlessly. It is interesting that Hippocrates already wrote that medicine has three aspects: 1.the art of curing, 2.the art of alleviating suffering, and 3.the art of knowing when to stop or not even begin a treatment which is senseless.

In this respect we should mention the Declaration of Madrid, unanimously adopted on 5 October 1987 by the World Medical Association: 'Euthanasia, that is the act of deliberately ending the life of a patient, even at the patient's own request or at the request of close relatives, is unethical. This does not prevent the physician from respecting the desire of a patient to allow the natural process of death to follow its course in the terminal phase of sickness.'

This Declaration is in agreement with the declarations on bioethics, which so far have been put forward by the Council of Europe and CAHBI. In Recommendation 779 (29 January 1976) on the rights of the sick and dying the Parliamentary Assembly of the Council of Europe stated: 'Considering that the doctor must make every effort to alleviate suffering, and that he has no right, even in cases which appear to him to be desperate, intentionally to hasten the natural course of death.' On 8 December 1988 the Dutch Health Minister informed Parliament that a Dutch request to the Committee of Ministers to study the juridical, ethical and medical aspects of euthanasia was rejected by the Committee, on the advice of CAHBI, as such a study was deemed neither suitable nor opportune. The reasons given were the foreseeable problems with Article 2 of the European Convention, as well as the fact that in the eyes of the governments of the member states of the Council of Europe euthanasia should remain a punishable act.

Once we have ascertained that the medical ethics which agrees with the European Convention is the same as Hippocratic ethics, then we come to our second task which is to complement this ethics with the appropriate ethics for biomedical research. This of course is the prerogative of CAHBI, but from the foregoing considerations some conclusions are immediately apparent in regard to such questions as experiments on humans, artificial insemination, *in vitro* fertilisation and prenatal investigation.

As regards experiments on humans, we may refer to the Declaration of Helsinki, accepted by the World Medical Association in 1964. As man undergoes an uninterrupted development from conception until death, the unborn human should be regarded, as was argued before, as having the same right to protection as the adult. Induced abortion and the use of fetal material obtained by it, and also experiments on living zygotes and embryos should be forbidden.

As the child has a right, if possible, to know his parents – if only to prevent consanguine marriage – artificial insemination should only be allowed if the donor of the used semen is known.

*In vitro* fertilisation, which implies experimenting with humans and the rejection of those zygotes who do not seem fit, should be forbidden. Besides, nobody can be sure that no harmful effects may manifest themselves at a later age.

Prenatal investigation should only be allowed if it is necessary in order to detect a fetal disease which can and must be treated *in utero*.

### 4. Other ethical systems

Finally, besides the question of whether Hippocratic ethics agrees with the European Convention, we should also answer the question whether this applies to the other bioethical systems as well. We should therefore ask ourselves on which principle each system is based and what kind of society will be the result if this system is accepted.

Thus in an Editorial of *California Medicine* (September 1970), the official organ of the Californian Medical Association, a 'New Ethics for Medicine and Society' is described. This ethics is based on the assumption that men are not equally valuable. Overpopulation was threatening and in the future not every quality of life would be acceptable, which means that doctors should decide, by means of certain criteria, who should be allowed to live and who not. Next to birth-control death-control should also be applied, and we doctors should now already prepare ourselves for this task.

It is clear that such an ethical system does not agree with the Universal Declaration and the European Convention: it is not based on the same principle and it is not aimed at the same ends. We therefore seem to be allowed to conclude that the approach used in this paper is a valid way to determine which bioethical system does agree with the ideals of the Council of Europe and which does not.

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# Identity and Status of the Human Embryo

Summary of a document of the Italian Catholic University Centre for Bioethics, Rome

During the 1988–1989 study sessions the Board of Directors of the Italian Catholic University's Centre for Bioethics focused on the theme of the identity, the status and the moral and legal protection of the human embryo with a multi-disciplinary approach. This theme is still at the basis of many debates on bioethics raising the problem of safeguarding the human embryo and its identity and status.

In their document the Centre's Board of Directors have highlighted the biological, philosophical, legal, psychological, ethical and theological aspects, and have decided that the result of their considerations should be concentrated in a document, to offer the opportunity for dialogue and for a deeper understanding.

From a biological point of view the document deals with two series of data which come from the study of the zygote and of its formation and development. These data suggest that during the process of fertilization, as soon as the oocyte and the spermatozoon (two cellular systems teleologically and differently programmed) interact, a new system immediately begins. The biological centre or coordinating structure of this new system is the new genome which contains and conserves, like a frozen memory, a clearly defined design-project. This genome identifies the one-cell embryo as biologically 'human' and specifies its individuality with essential and permanent 'information' for the gradual and autonomous realization of such a project which begins at fertilization without interruption, in a continuous way. These data lead to one single conclusion - undeniable in the logic of biology – that is at the fusion of the gametes a 'new human cell', equipped with a new information structure, begins operating like an individual unit tending towards the complete expression of its genome, which manifests itself in a totality and which constantly and autonomously organizes itself until it forms a complete human organism.

The Board of Directors is aware of the opinions of some authors who suggest different moments of the beginning of the individual human being (when the 'primitive streak' is visible, or twin separation can no longer occur, and so on), but even though the effort made in elaborating these opinions is respected, the arguments that these opinions are based on do not invalidate the Board of Directors' conclusions.

Despite being undeniable, the conclusions inferred from the biological data are obviously insufficient by themselves to solve the problem. Philosophical reflexion can therefore provide a deeper understanding, highlighting the relationship of the above-mentioned biological conclusions with the concept of the individual human being in its totality, and at the same time, explaining the relationship between the period of embryonic life and the expansion of the fully developed personality. Moreover, philosophical reflexion allows one to overcome any dissociation between the 'biological' and 'socio-psychological' component of the person, and therefore between the 'ontological' and 'phenomenological' aspects of the person himself. There are two possible conclusions of this reflexion in the Board of Directors' view: the former is that the human embryo is not pure potentiality but it is living and individualized substance: the embryo is potentially a child or a man but it is not potentially a human being. That is what it already actually is. Therefore, before fertilization, the spermatozoon and the ovum only possess a mere possibility of making up a unified system and entity. The zygote, however, is an individual with its own life, and with its own identity given to it by a single unifying substantial principle. The fact that, from a psychological and social point of view, the human being fulfils himself as a personality along a long path of relationships and cultural contributions, does not exclude, but rather requires, from an ontological point of view, that the human being should possess that which will allow him to fulfil himself as a personality, from the beginning of embryonic life, and therefore he must obtain the respect due to a human being.

The latter conclusion requires an explanation of the notion and the concept *telos* or 'aim'. The aim of a being is what explains the existence of such a being and reveals its why and its meaning. However, this aim is not simply at the end but is at the beginning of a being's development like a direction giver. One might not recognize this aim in its fullness but that is no reason for excluding it from the beginning: if it were not there from the beginning as a direction giver there would be no chance of completion and that being would not be what it is either before or later.

The judicial aspects are also considered, pointing out the duty to legally protect the embryo if one recognises it as an individual human being.

In the last part of the document ethical and theological points of view are discussed, and an important role is assigned by the Board of Directors to the human rationality. So, according to the needs of human rationality – and then also with no necessary reference to revelation which moral theology refers to – any intervention on the human embryo can only be considered moral, in the Board of Directors' opinion, if and in the measure in which it conforms to the human embryo's nature or its identity in the sense that it respects and never contradicts it. And since the 'nature' or the embryo's own identity is that of a human being, the behaviour in respect to the human embryo is only moral if and in the measure in which it considers and treats the human embryo like a human being, like any other human being.

Antonio G. Spagnola, MD Rome

### Jane Mellor, Research Officer, CARE, London

7–10 June 1990 Maastricht Exhibition and Conference Centre Holland 30 Groups from 19 nations attended.

The Congress was opened at 7 o'clock on Thursday evening by Mrs Pit Bakker, President of the Dutch Society for Voluntary Euthanasia, and Derek Humphry, co-founder of the USA-based 'Hemlock' Society and President of the 'World Federation of Right to Die Societies'.

Mrs Bakker expressed disappointment at the small number of delegates present (250 instead of the anticipated 600). However, it was the absence of the German Right to Die Society that gave the organisers most cause for concern.

In 1988 at the San Francisco conference, Hans Trott, President of the German Society, had expressed grave reservations about doctors performing active euthanasia. Even if doctors are acting at the request of the patient, he argued, it will 'come to the point of the Nazis in the past'. This was clearly the cause of the German absence which Mrs Bakker failed to explain.

Derek Humphry traced the history of euthanasia movements around the globe and lamented the anti-euthanasia feelings caused by the spread of world Christianity during the last 2000 years. In post-Christian times, he argued, we must abandon the trappings of religion and allow new values to emerge.

Maurice De Wachter, Director of the Institute of Health Care Ethics, Maastricht, spoke about the need for a clear definition of the term euthanasia.

'Self determination' and the 'right to choose' was the key theme on Friday. However not all the speakers were in favour of euthanasia and some raised serious problems. For example, the psychologist Dr Zwart mentioned some conceptual tools which should make us wary of taking a request for euthanasia as an example of self determination. Transference, for example, is the word psychoanalysts use to express compliant behaviour. 'In highly constrained situations [such as illness], people do tend to comply with the judgment of others.' In other words a patient may well agree with adoctor who suggests euthanasia in order to please the doctor. Other evidence to this effect emerged during the three days.

At the other end of the scale, Dr Helene Dupuis issued a veritable tirade of abuse against those with objections to euthanasia. 'Whoever would want to deny another person a decent and gentle death must be a very cruel person' she fumed.

One of the speakers was Chief Prosecutor Josephus Jitta who declared his view that individuals should have the right to choose on

this issue. More importantly, he explained that doctors within his district will not be prosecuted (euthanasia is still formally illegal in Holland) if they meet certain criteria: 1) they must report the death to the police; 2) the request must have been made freely, over time and the person must be in 'unbearable suffering'. Particularly disturbing was the fact that the Chief Prosecutor admitted he would no longer pass euthanasia cases to the Attorney General as before. Euthanasia – although still illegal – is becoming part of everyday life because of the conscious decision not to prosecute the doctors who perform it.

Friday afternoon's debate was given over to discussion of incompetent patients. What of those people who cannot request euthanasia for themselves, either because they are severely damaged by accident or disease or because they are newborn babies? 'Living wills' signed when the patient is competent offered one way around the problem. But what of those who had no living will-the newborn for example? Some speakers did not feel that such 'beings' should be killed. Others thought they should. 'The prolongation of life becomes meaningless when that life has no value', said Dr Musschenga. And whose life is of no value?

Perhaps Dr Admiraal answered this best of all. For years Admiraal has practised euthanasia in the major cancer hospital unit at the Reinier de Graaf hospital in Delft. He had never campaigned for a change in the law but recently had changed his views. When asked why, he gave this reply: 'the circumstances we have today, described by Josephus Jitta, will soon spread to all districts of Holland, so I thought, I could live without a change in legislation. But after talking to Jitta I realise it is not so. Euthanasia must be legalised because there is more work to do. We are speaking about the handicapped newborn, we are speaking about coma patients....' Clearly these categories of incompetent patients are considered to have lives not worth living and as such are likely to be targeted for euthanasia over the coming years.

Saturday began with an account of the young Dutch Hospice movement. There are only 2 hospices in Holland, though 50 different groups are involved in giving home care to the sick and dying in their own homes. The real surprise came in the opening statement: 'The Dutch Hospice movement as an organisation takes no stand against euthanasia. We simply put all our energy into supporting people to live fully until they say goodbye.' Asked later whether hospice doctors would practice euthanasia, the speaker said yes, although this had not been necessary so far.

The discussion then turned to the role of the so-called 'Members Aid Service'. Led by Jean Tromp Meesters, this group helps people to die, by putting them in touch with pro-euthanasia doctors; by advising them on their rights as a patient; by teaching them how to raise the issue with their doctor.

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The final session was chaired by a pro-euthanasia MP, Mr Kohnstamm and led by I. van der Heuvel who was a Euro MP until late 1989. We have to play the European card'...'in the interests of all the incurable and dying people in Europe we cannot concentrate on the Dutch island only', they said.

Both MPs felt that euthanasia should be legalised in all countries of Europe and I. van der Heuvel explained how this could be done: 1) by media exposure of euthanasia and by Dutch doctors visiting other countries and sharing their experiences; 2) by encouraging the European Parliament to move into the field of health law; 3) getting discussions in the Council of Europe with the aim of encouraging the establishment of a Commission on the Rights of the Dying, similar to the Commission on Human Rights. I. van der Heuvel stressed that she is a Christian and that her pro-euthanasia position is a Christian one.

The Congress ended with an award-winning film which showed how one woman had a 'beautiful death' through euthanasia.

# DEATH WITHOUT

# DIGNITY

EUTHANASIA IN PERSPECTIVE

Edited by Nigel M. de S. Cameron with a foreword by Bp Maurice Wood

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# The Status of the Human Embryo

Summary of the Report of the Prof. Dr G.A. Lindeboom Instituut, Ede, Holland

The issue of the status of the human embryo, especially of the preimplantation embryo, has become much more urgent by the development of the *in vitro* fertilisation.

In the literature a number of different positions can be distinguished with respect to this problem. In these positions different characteristics are put forward as decisive criteria with respect to the moment when the embryo deserves full protection. These are: the potentiality of the embryo, the relationships in which and the intention with which the embryo is created, the individuality of the embryo that only after fourteen days would be fixed, or the personality, that would be strictly related to brain-activity and that therefore could arise only about six weeks after conception.

In all these views the embryo deserves only relative protection during the first fourteen days after conception.

In contrast the conceptionistic view defends the humanness and therefore the full protection for the embryo, referring to the unique, irreversible character of conception, which at the same time is the beginning of a dynamic process of development that continues without specific caesuras until the organism dies, either as an embryo, a foetus, a child or an adult.

In contrast the conceptionistic view defends the humanness and therefore the full protection for the embryo, referring to the unique, irreversible character of conception, which at the same time is the beginning of a dynamic process of development that continues without specific caesuras until the organism dies, either as an embryo, a foetus, a child or an adult.

All these approaches come to a conclusion with respect to the status and humanity of the embryo on the basis of certain scientifically observable characteristics.

This is methodologically impossible. (Natural) science methodologically ignores the relationships in which the object of study presents itself and the question of its meaning. This question ultimately is a matter of world view. The link between world view and science is provided by philosophy. The scientific method, therefore, is based on philosophical presuppositions. A statement about the status of the human embryo and the meaning of the human being never rests only on scientific data and therefore cannot be proven by it, but always implicates, implicitly or explicitly, a philosophical decision which, in its turn is founded on a world view, a belief. Grounded on the historical-Christian faith in creation, we think the origin of man lies in the creative Word of God. The humanness of man, therefore, always transcends the observable by the senses, while at the same time one cannot speak about it apart from the visible manifestation of it. Right from the beginning of the corporal side of the human being – or biologically speaking, of the human organism – a human being in the full sense of the word is involved. The embryological data make clear that the human organism begins at conception. From conception on the human embryo has its own identity, contains unique genetic information, necessary for the continuation of its dynamic development, that is dependent on and influenced by milieu factors, but does not show fundamental caesuras. The embryo is representant of the species and as such a human individual, a human organism.

In its development the human embryo is specifically human, right from conception, and is oriented towards the realisation of yet latent, typically human functions. That at a certain moment not all potential possibilities are actual realities, is in fact true for man during his whole lifetime!

The environmental influences, that can be infinitely varied, implicate that in no stage of development humanness can be described or explained in abstract notions like information, potentiality, individuality, personality (as bound to brain function). Here the scientific description itself indicates (but cannot prove) the impossibility to 'fix' the humanness of man in scientific concepts, which for reasons derived from philosophy of science, was already shown to be impossible.

However, the embryological data do justify (as we saw) the view that conception is the beginning of the human organism.

So, the idea with respect to the humanness of the zygote, based on our world view, is not contradicting the embryological data but in accordance with them and therefore relevant for biomedical research. The fundamental ethical conclusion must be that from the moment of conception the human embryo should be treated in the same way as man in any other stage of his life.

### In-Vitro-Fertilisation

Chapter I: *In Vitro* Fertilization A medical evaluation by W. G. M. Witkam

### Summary

Clinical *in vitro* fertilization, as a practical procedure, contains a number of components whose laboratory stage is indispensable by definition. Current practice of the laboratory stage is based on the results of earlier historical experiments with human *in vitro* conception and *in vitro* embryology.

The *experimental* aspect of *in vitro* fertilization, discussed in part A of this chapter, is the 'leitmotiv' extending from the past *via* current practice to further biomanipulation of the human embryo in the future. The years until the birth of the first 'test-tube baby' in 1978 can be called the period of the 'pioneers', most of whom were engaged upon embryology *in vitro*, and for whom in the beginning implementation was not the main concern. The *history* of the ethical repercussions in those days would seem to be pertinent to the current situation, given the permanent basic ethical question of whether the use of the living human conceptus as a subject of research in experimental embryology can be justified. The freedom of scientific research in this area is after all at odds with the desirability of ethical protection for the human embryo. An analysis is made of the studies that have been undertaken of the ethical repercussions during the historical 'pioneer period' (§1).

We find the options and assumptions concerning laboratory conception recurring as the basis of *in vitro* fertilization carried out in a clinical context since 1978. Indeed, current clinical practice of human *in vitro* fertilization and embryo-transplantation is definitely still in the experimental stage and researchers continuously express the desire to pursue the investigation started by the pioneers in order to improve the results of treatment. At the same time they state their wish to make use of 'spare' embryos that become available as a result of clinical *in vitro* fertilization for fundamental and applied *research* within the framework of various biomedical questions which go beyond the limits of the original range of application, that of infertility treatment, and even beyond the boundaries of traditional medical science (see Editorial in *The Lancet* of 2-2-1985).

At first sight there seems to be, in the increasing number of publications on in vitro fertilization, no lack of ethical perceptions. An important part of these writings consists of what is sometimes referred to as 'soft law': the directives, recommendations and advice drawn up by organizations of professional practitioners, social institutions active in the area of 'research and society' and government agencies, as forerunners of a process of issuing rules in a number of countries that has barely started. As a result of earlier ethical considerations, these texts are a major source of study material for the description of the various ethical positions (§2). The ethical discussion already in progress in countries where the pioneer stage occurred and which consequently are at a historical advantage, might benefit the country of Anthonie van Leeuwenhoek (1632–1723) and Reiner de Graaf (1641–1673), where one can hear complaints about a certain leeway as regards biomedical research in this field (cf. 'IVF: The Netherlands are behind', Medisch Contact 41, no. 23, 1986).

The specifically ethical aspect that distinguishes test-tube fertilization from other forms of artificial reproduction is that of the metaaspects of the earliest development of man and the ethical status of the human embryo with the attendant consequences for the desirability of its protection. It has reached the point that not only public discussion in the media, but also the ideas put forward by experts in professional publications seem to be a recapitulation of the debate on induced abortion that took place earlier in numerous countries. No matter how much both problem areas and the attendant ethical repercussions may have influenced each other, more recent biomedical facts having surfaced also from *in vitro* studies in the course of the last few years, can deepen our insight into the character of IVF as a substitute of the natural environment. This might also make it possible to move the current ethical debate in another direction. In §3 a study is made of the relevance of the insight now available for a judgment on *in vitro* fertilization and cryo-preservation as a *biomanipulation* of the human embryo.

In part B clinical IVF + ET is discussed. The medical aspects of this therapeutic innovation which are important for ethical evaluation deal with its safety and effectiveness, also in comparison with alternative techniques (Appendix). The selection of conceptus for ET, which in actual practice is indispensable, is ethically contestable and reveals that IVF is more than just a method of treatment for certain forms of infertility: it is a breakthrough, and as such repeatedly hailed as 'the most spectacular biomedical event of the 1970s' (Grobstein), in the direction of complete control over human reproduction. The pioneers already had clear eugenic views: selection of individuals on the basis of their possession of a certain genome and modification of the human genome. Tissue culture of the human embryo will, also in the future, be considered the necessary starting-point ('experimental model') for both research and applications, including 'genetic engineering'. The scope for IVF is not limited to what concerns the would-be parents and the gynaecologist in attendance. In view of the meta-aspects the problem goes beyond the scope of the 'elementary' medical-ethical situation, the physician-patient relationship.

The lesson of the Prometheus-myth is that 'great abilities are a great danger, unless they are used with great wisdom and this use is limited to those who have an overall view of the consequences of such use'

A 'Promethean situation' arises from the large-scale consequences that our decisions will entail, both worldwide and with regard to the future. The lesson of the Prometheus-myth is that 'great abilities are a great danger, unless they are used with great wisdom and this use is limited to those who have an overall view of the consequences of such use' (Rattray Taylor). Present-day knowledge from research and application in the field of human in vitro fertilization, through comparison with results in other areas of biological research, can lead to an extrapolation in the direction of a future consisting of a further realization of a tendency towards biomanipulation of the human embryo, which is already undeniably present in the current situation and will increasingly challenge prospective medical ethics. An 'ethics of means' is no longer sufficient; we also need an 'ethics of ends', if we do not want to go forward with a medical science that is 'adrift'. Adrift to the extent that there is in medical circles a lack of global consensus concerning the question which of the biotechnical innovations that present themselves fit within the framework of the therapeutic options of medical science. The question about the metabiological status of the human embryo and the significance of the human pre-implantation period will be answered in a subsequent report, which will also make use of recent perceptions originating from human embryology and developmental biology [48a]. This seems to be the necessary course, as the earliest stages of human development conceal themselves from everyday observation and the significance of the scientific data for a philosophical-ethical point of view has to be examined.

### Chapter II: In Vitro Fertilization An ethical evaluation by W. H. Velema

### Summary

This contribution has as its point of departure an ethical approach which is bound up with a specific philosophy of life, namely the Christian faith. This system is in sharp contrast with argumentethics advocated by many. The latter type of ethics overlooks the fact that arguments originate somewhere and serve a particular purpose. We intend to discuss arguments as well as background and aims. The requirement that the arguments should be communicable and capable of being universalized must not mean that the discussion is to be limited to specific arguments within a broad philosophical frame of reference, and this we are willing to do.

*In vitro* fertilization is applied as a treatment in cases of infertility. The Bible calls fertility God's blessing. The reproduction is embedded in the covenant between two persons.

We look upon *in vitro* fertilization as a technicalizing of procreation. It is separated from the communion between husband and wife, which is a sealing of the marital covenant. Husband and wife are made donors of sperm- and egg-cells. Technicalizing implies that experiments are carried out. These experiments with embryos assume the acceptation of abortion.

Little is known as yet about possible damage that can be sustained by the embryo during the procedure, for example through freezing and thawing. Technicalizing itself as a fertilization outside the womb profoundly influences the relationship between mother and child in the first stage of pregnancy.

Furthermore, IVF means that a third party (the doctor and his staff) stands between husband and wife.

Little is known as yet about possible damage that can be sustained by the embryo during the procedure, for example through freezing and thawing. Technicalizing itself as a fertilization outside the womb profoundly influences the relationship between mother and child in the first stage of pregnancy.

The number of embryos produced is larger than the number of children wanted, in order to offset possible failures. At most one in ten embryos is successfully implanted. This means that some embryos are wasted so that another can produce a child.

Some kind of selection is to be established. Nobody wants to supply a bad or inferior product. Therefore there is a quality check with its attendant consequences. This introduces the idea of the 'makability' of man, even though in actual practice this course is still very limited.

This treatment makes husband and wife the donors of sperm-and egg-cells. There are at least seven main variants possible of combinations of donors of sperm and egg cells with would-be parents and

surrogate mothers. This presents the lawgiver with great problems, and – later on – the child itself as well. Who is my father? Who is my mother? What moral responsibility rests with whom?

Next there is the problem of the embryo's status (see also [2]). We are in favour of regarding the embryo as a human being from the moment of its conception. Only in that case is justice done to Biblical data, to the fact that the embryo is an human being. Therefore it ought to be protected right from the start. In our opinion the idea of an increasing worthiness of protection that is related to the growth of the embryo has to be rejected.

We do not trivialize the suffering resulting from childlessness. However, *in vitro* fertilization gives rise to such weighty objections that this method should not be used to counteract childlessness. With *in vitro* fertilization a boundary is crossed and no return is possible. Indeed, it is possible to argue for limiting the damage. This plea, however, is not an essential defence against all the injustice being done to embryos.

In our attempt to lift the burden of childlessness we ought to look for other ways which are ethically acceptable.

Chapter III: In Vitro Fertilization A juridical evaluation by A. van der Linden

### Summary

This contribution gives an outline of the current situation in respect to the right of descent. The right of descent deals with the relationship between parents and children. Generally it is absolutely clear who are the child's mother and father. The child has the right to this certainty. Lack of it is not in the interest of the child. It can lead to negative implications as regards the child's psycho-social development.

The right of progeny does not exist. However legitimate the wish to have children may be, the right to have them cannot be established. Not on the grounds of our basic rights, nor on the basis of *ETHR*. Contrary to this children do have a right to a father and a mother. Depriving a child of a father or a mother can never be in the child's interest.

### Depriving a child of a father or a mother can never be in the child's interest.

Being born in wedlock provides maximum certainty. Usually all forms of parenthood coalesce in this case and the regulation of authority does not create any problems. Children should never be allowed to fall victim to their having been born out of wedlock. The position of legitimate and illegitimate children ought to be juridically identical.

Not everyone can have a child. The possibilities of medically treating childlessness have been enlarged in the last few years through various types of artificial reproduction techniques (cf. chapter I).

Besides medical assistance would-be parents can make an appeal to institutions for aid to youths (foster care) and adoption. Often this

option does not lead to a solution because the number of children available to be put into contact with would-be parents *via* these channels is insufficient. Then the question arises to what extent the medical treatments just mentioned are desirable and acceptable.

In our opinion the use of donor-gametes, whether donor-sperm or donor-egg-cells, should be rejected, as should all forms of surrogate motherhood. Should the government in future legislation leave room for these techniques with their attendant descent constructions – and we hope they will not – the least harmful alternative seems to be to give the children, resulting from these constructions, at the very least the right to information concerning their parentage. All relevant information ought to be registered with that purpose in mind.

Given the status of the human embryo, the use of embryos for medical experiments in which they do not survive ought to be rejected; the same holds good for the creation of more embryos than can be put back during one cycle of IVF treatment. We think it advisable for the government to pursue a policy that encourages IVF treatment to be replaced by infertility treatments in which there is no fertilization *in vitro* and fertilization is not separated from sexual intercourse. Any post-mortem use of gametes ought to be prohibited explicitly on the fact that in this process the child is deprived of one of the (biological) parents in advance.

We consider it the duty of the government to provide the child, in the middle of fast moving medical-technical developments, with legal protection that is based on a clear sense of justice, in the child's interest.

### Recommendations to the Government and Parliament by the Prof. Dr. G.A. Lindeboom Instituut

### Considering that

a. In vitro fertilization (henceforth IVF) treatment is a burdensome step, above all psychologically, with still a small chance that it will result in the birth of a living child (chapters I and II),

b. This technique opens the door to all sorts of other manipulations involving human procreation, subverting a number of basic values
in our society such as: respect for human life from its conception (cf. The status of the human embryo, Report by the Prof. Dr. G.A. Lindeboom Institute, no. 1, Ede, 1988); monogamous marriage as a context for procreation and upbringing of children; the right of children to a father and a mother and knowing their own parentage (chapters I, II, III),

c. Infertility on the one hand is relatively often caused by a certain lifestyle and greater emphasis on prevention would be a more logical course, and on the other hand it often has a psycho-somatic background and ought to be treated primarily on that level (chapter I, II),

d. For the somatic causes of infertility there are alternatives for IVF which would avoid a number of objections (notably b and e): surgery on the Fallopian tube and other less radical forms of artificial reproduction (see chapter I, Appendix), and which as far as we know now are less rather than more expensive than IVF (per live birth),

e. IVF is a technique which deals with human embryos in a manner that is open to question to say the least, and which in our opinion ought to be rejected (chapter II and Supplement I),

f. Application of IVF and other artificial reproduction techniques outside the context of marriage can result in all sorts of legal difficulties and uncertainties for the children (chapter III),

the Prof. Dr. G.A. Lindeboom Instituut urges the Government and Parliament:

1. To pursue at the very least a policy of discouragement with regard to IVF, if they do not prohibit it altogether, specifically by not including this treatment (or allowing it to be included) in insurance coverage, neither in employees' coverage (compulsory medical insurance Act), nor in special medical coverage ('AWBZ'); neither should its inclusion be permitted in the coverage of private insurance companies,

2. To stimulate research into alternative ways of treating infertility which make no use of fertilization *in vitro*; only if the alternative methods have proved to be safe and effective, and are morally acceptable, can inclusion of these methods in the provisions of medical insurance policies be considered,

3. To make it illegal to produce human embryos other than with a view to procreation, and on the condition that they are put back into the womb of the donor of the gametes being used, should IVF remain permissible,

4. To stimulate a prohibition of all research on embryos that is not specifically meant for the benefit of the embryos concerned,

5. To make it illegal to provide medical assistance and commercial mediation to further any kind of surrogate motherhood,

6. To grant children born with the assistance of donor gametes - should this remain permissible, which we hope will not be the case - the legal right to be informed about their parentage,

7. To make illegal the post-mortem use of gametes in artificial reproduction techniques.

# The Danish Council of Ethics: Second Annual Report, 1989

Extract giving Recommendations for regulations for protection of fertilized human ova, living embryos and fetuses

Pursuant to the Law on the Danish Council of Ethics and regulation of certain biomedical experiments, the Council must submit recommendations to the Health Minister on the stipulation of legislated regulations about protection of fertilized human ova, living embryos and fetuses. Therefore, the Council has prepared a recommendation for a set of regulations. The following presents two principally different recommendations for protection of fertilized human ova, live embryos and fetuses, which reflect the majority and minority recommendations in the first part of chapter 5. In addition, there is a set of regulations about artificial insemination. These regulations are at the same time summaries of chapters 5 and 6. The same definitions and concepts are used as in those chapters.

The two principally different attitudes in the Council to reproduction technology, however, do not lead to complete agreement in the conclusions within the majority and minority opinions. Thus, several Council members within the majority agree with the minority on some points and *vice versa*.

On the points where a minority wishes to express a separate opinion, this is presented as a minority recommendation with the proposers in parentheses.

# The majority recommendation for regulations for protection of fertilized human ova, living embryos and fetuses

The majority consists of: Bolund, Garnov, Kallehauge, Sejer Larsen, Mikkelsen, Pindborg, Rasmussen, Rømer Rassing, Rehof, and Reintoft.

### **Chapter 1**

### The field of application of the regulations

1.1 The regulations have the objective of protecting fertilized human ova, living embryos, and fetuses in connection with experiments and individual treatment trials.

### Chapter 2

### Definitions

- 2.1 By experiments is understood interventions where data collection according to a preconceived protocol produced on the basis of general and internationally recognized standards for scientific work, has as its purpose to confirm or invalidate a hypothesis of scientific value or undertake a systematic and goal-directed collection of data. The regulations do not cover register research, behavioral research, etc.
- 2.2 By treatment is understood a common, recognized and

tested method which has as its purpose to prevent, diagnose or treat disease or relieve suffering and pain.

- 2.3 By individual treatment trials is understood medical measures which have not yet been recognized as treatment and which to a certain degree presuppose experiments before they can be recognized as treatment.
- 2.4 Fertilized human ova, embryos, and fetuses are regarded as living when they possess the potential for developing into an individual or when signs of life can be demonstrated.
- 2.5 By harmful effect is understood a lasting effect which impairs bodily functions.
- 2.6 The designation fetus is used until birth if the fetus is in the uterus of the woman, and until the end of the twenty-eighth gestational week if the fetus is outside the uterus.
- 2.7 The genetic mother is the woman from whom the ovum originates.
- 2.8 The biological mother is the woman who carries the fetus during pregnancy.
- 2.9 The genetic father is the man from whom the semen originates.

### **Chapter 3**

# Conditions for experiments with and individual treatment trials on fertilized human ova, living embryos and fetuses

- 3.1 Consent can only be regarded as informed consent when the person who consents, in advance and in suitable form, in writing and speech, has received such guidance and information that the decision is taken on a relevant basis. Consent must be submitted in writing. (Chapters 5 and 6 stipulate who is to give consent in the various situations.)
- 4.1 Experiments and individual treatment trials on fertilized human ova, living embryos and fetuses can take place provided that:
  - informed consent has been given

- the experiment or the individual treatment trial is sanctioned by a control agency

- it is not assumed to entail genetic alterations which can be carried on in future generation

- by the experiment significant results can be obtained which cannot be obtained otherwise

- the experiment can improve the reproductive technique or be beneficial to future treatment - it does not inflict upon the embryo or fetus unnecessary suffering

- it is not assumed to cause harmful effects on the human fertilized ovum, embryo, fetus, or the mother.

4.1a *Minority recommendation* (Bolund, Mikkelsen, Pindborg, Rasmussen):

- in addition, experiments may be conducted on fertilized ova and live embryos and under very specific conditions on fetuses, even if the experiments could have harmful effects. A prerequisite is that the fertilized ova, embryos and fetuses would have perished, regardless of whether the experiment had been undertaken or not.

- 4.2 If there is imminent, significant danger that the fertilized human ovum, live embryo, or fetus will perish or suffer serious injury, emergency individual treatment trials with the purpose of securing survival or hindering disability may be undertaken. These individual treatment trials should subsequently be reported to the control agency.
- 4.2a *Minority recommendation* (Rehof, Reintoft): 4.2 is not included.

### **Chapter 4**

### In Vitro Fertilization

- 5.1 *In vitro* fertilization can be undertaken when informed consent has been given for this.
- 5.2a *Minority proposal* (Rasmussen): *In vitro* fertilization ought only to be offered to women who live in a stable cohabitation with a man.

### **Chapter 5**

### Freezing of Surplus Fertilized Human Ova

6.1 Fertilized ova can be frozen provided that,

- informed consent has been obtained. If one of the partners revokes his or her consent, the fertilized ovum should be destroyed

- the fertilized ovum is destroyed at the latest after one year or if one of the parents dies, unless particular conditions speak against this

- the storage takes place at authorized hospitals or with specifically authorized specialists.

### Chapter 6

### Donation of Unfertilized and Fertilized Human Ova

- 7.1 Donation of unfertilized and fertilized ova is allowed provided informed consent exists.
- 7.1a *Minority proposal* (Reintoft): Donation of human ova is not allowed.
- 7.1b Minority proposal (Sejer Larsen):

Donation of unfertilized ova is not allowed.

Minority proposal (Rehof): Donation of fertilized and unfertilized ova is allowed for purposes of pregnancy when informed consent has been given.

1

- 7.2 Custody is with the biological mother and her husband or cohabitant. This occurs with full and irrevocable family change from donor to recipient family.
- 8.1 The donor must be ensured full anonymity.
- 8.1a *Minority proposal* (Garnov, Sejer Larsen): Children should have the right to obtain information about their genetic parents' identity. This must not entail consequences for name or inheritance.

### Chapter 7

7.1c

### **Prohibitions**

9.1 The following experiments are not allowed:

 experiments which have as their purpose to make it possible to produce genetically identical persons
 experiments which have the purpose of making it possible to produce human beings by fusion of genetically different embryos or parts of embryos before implantation in the uterus

- experiments which have the purpose of making it possible to produce human beings with a genome including components from other species (hybrids)

- experiments which have the purpose of developing human beings without fertilization

- implantation in the uterus of surplus fertilized human ova which have been the subject of experiments which might be harmful

- implantation of human fertilized ova, embryos or fetuses in the uterus of an animal, or implantation of fertilized ova, embryos or fetuses from animals in the uterus of a woman - genetic experiments and gene therapy on human gametes and fertilized ova or other kinds of gene therapy which lead to genetic changes which can be carried on in future generations

- experiments with gametes which are used for fertilization where a development to an individual takes place.

- 9.2 Fertilization of human ova is not allowed when the purpose is solely experimental.
- 9.2a Minority proposal (Bolund, Mikkelsen, Pindborg, Rømer Rassing):
   9.2 is not included

9.2 Is not metuded

10.1 Experiments where the following procedures or techniques are employed are not allowed:

> - procedures which make it possible to produce human beings by fusion of genetically different embryos or parts of embryos before implantation in the uterus

> - fusion of human gametes with gametes from other

### species

- fusion of human embryos with embryos from other species - every technique which might lead to development of an individual without fertilization.

- 10.1a Minority proposal (Bolund, Mikkelsen, Pindborg, Rasmussen, Rømer Rassing):
   10.1 is not included.
- 11.1 Sale of fertilized human ova, embryos and fetuses or parts of them is not allowed.

### **Chapter 8**

### Sanctioning

- 12.1 Experiments and individual treatment trials on fertilized human ova, embryos and fetuses may only take place with sanction from the control agency.
- 12.2 The control agency can stipulate more detailed conditions for the sanctions given.
- 12.3 The control agency can stipulate requirements about which information an application for sanction should contain.
- 12.4 The control agency stipulates requirements that those responsible for experiments or individual treatment trials on fertilized human ova or fetuses must submit or produce information.
- 13.1 The control agency can at any time revoke a sanction or stipulate new conditions when this is considered necessary to protect fertilized human ova, live embryos or fetuses against dangers of harm or suffering.
- 13.2 The control agency can partly or completely exempt concrete experiments or individual treatment trials on fertilized human ova, embryos and fetuses from the requirement for approval.
- 13.2a *Minority proposal* (Garnov): 13.2 is not included.

### **Chapter 9**

### **Authorities**

- 14.1 The control agency consists of ... who are appointed by ... such that there is a majority of lay persons and that a broad professional spectrum is represented.
- 14.1a *Minority proposal* (Pindborg): There must be parity between lay persons and professionals.
- 14.1b *Minority proposal* (Garnov): The control agency consists of lay persons.
- 15.1 The control agency must safeguard the ethical considerations in connection with experiments and individual treat-

ment trials on fertilized human ova, embryos and fetuses.

16.1 The control agency can sanction and must supervise all experiments and individual treatment trials with fertilized human ova, embryos and fetuses.

### Chapter 10

### Supervision and Control

17.1 The control agency can state the injunctions or prohibitions which are regarded as necessary for safeguarding the observance of these regulations.

### Chapter 11

### Professional Secrecy and Penalty Clauses

The Council has not found it appropriate to produce proposals for regulations on this subject at this time, but awaits the further public discussion.

### Chapter 12

The Coming into Force, etc.

- 18.1 These regulations come into force...
- 19.1 Simultaneous with the coming into force of these regulations, Law No. 353 of June 3rd, 1987, section 11, is repealed.
- 20.1 These regulations will be taken up for revision during the parliamentary session years 199... to 199....
- 21.1 These regulations do not apply for the Faroe Islands or Greenland, but might by Royal Decree be put into force for those two parts of the country with the alterations relevant to particular Faroese and Greenland conditions.

### The minority proposal for regulations for protection of fertilized human ova, living embryos and fetuses

The minority consists of: Andersen, Bagger, Damsholt, Fasting, Gyldenholm, Jensen, Kjær.

### **Chapter 1**

Purpose

1.1 These regulations have the purpose of protecting human ova, living embryos and fetuses in connection with experiments and individual treatment and to phase out *in vitro* fertilization.

### Chapter 2

### Phasing out of in vitro Fertilization

The Health Minister will work out a plan for adoption in 1991 with

concrete proposals for rendering superfluous and phasing out *in* 11.1 *vitro* fertilization within a more specific time limit.

### **Chapter 3**

### **Prohibitions**

- 3.1 Experiments with fertilized human ova, living embryos, and fetuses from which they will not benefit are prohibited.
- 3.1a *Minority proposal* (Damsholt, Gyldenholm): Experiments can be undertaken on fertilized ova which do not entail direct intervention in the ova and which will directly benefit the woman who has produced the ovum, provided the conditions stated in 4.1 of the majority regulations are fulfilled.
- 4.1 Freezing fertilized ova is prohibited.
- 4.1a Minority proposal (Andersen, Damsholt, Gyldenholm) Fertilized ova may be frozen provided that informed consent exists. Insofar as one of the partners withdraws his or her consent, the fertilized ovum should be destroyed.
  the fertilized ovum is destroyed at the latest one year after the freezing or if one of the parents dies.
  the storage takes place at authorized hospitals or with specifically authorized specialists.
  they are only used by the woman who has produced the ovum.
- 5.1 Donation of unfertilized or fertilized human ova is prohibited.
- 6.1 Donation of semen is prohibited in connection with *in vitro* fertilization.
- 6.1a *Minority proposal* (Damsholt): 6.1 is not included.
- 7.1 Sale of fertilized human ova, embryos and fetuses or parts of them is prohibited.

### **Chapter 4**

### In Vitro Fertilization

- 8.1 *In vitro* fertilization must only be on offer to women who are married to or live permanently with a man.
- 8.1a *Minority proposal* (Andersen, Damsholt): 8.1 is not included.

### **Chapter 5**

The Coming into Force, etc.

- 9.1 These regulations will come into force...
- 10.1 Simultaneous with these regulations coming into force, Law No. 353 of June 3rd, 1987, section 11, is repealed.

- These regulations will be taken up for revision during the parliamentary session years 199... to 199....
- 12.1 These regulations do not apply for the Faroe Islands or Greenland, but might by Royal Decree be brought into force for those parts of the country with the particular alterations relevant to specific Faroese and Greenland conditions.

Nanna Damsholt and Arn Gyldenholm find, in addition, that in connection with the sanctioning of experiments in accordance with 3.1a, provisions ought to be in force which are identical to the majority regulations 12.14, 13.12, 14.1, 15.1, 16.1, and 17.1.

### **Regulations for artificial insemination**

- 1.1 Consent can only be regarded as informed consent when the person who consents, in advance in suitable form, in writing and speech, has received such guidance and infor
  - mation that the decision is taken on a relevant basis. Consent must be submitted in writing by the woman who is inseminated and, where applicable, by her husband or cohabitant.
- 2.1 Artificial insemination is allowed provided informed consent has been obtained.
- 2.1a *Minority proposal* (Bagger, Fasting, Gyldenholm, Kjær, Rasmussen):

Artificial insemination should only be offered to women who are married or living permanently with a man and provided informed consent has been obtained.

- 3.1 Human semen may be frozen provided that - informed consent is given
  - the storage takes place at a hospital or with specialists who have been authorized for this

- the number of inseminations is restricted. The maximal limit is fixed by the Danish Board of Health.

- The selection of donors must be done strictly from medical criteria and physical likeness with the social father.
- 4.2 Custody remains with the persons who have given informed consent, *cf.* section 1.
- 5.1 The donors are secured full anonymity.

4.1

5.1a

Minority proposal (Andersen, Bagger, Damsholt, Garnov, Kjær, Sejer Larsen):
Children should have the possibility of obtaining information about the identity of their genetic father. This must not have any consequences for the name or inheritance.

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