

## **Life before birth**

Allow me to start with a story.

It happened in the train between Strasbourg and Brussels. At one stop a young man enters the train. He comes and asks whether the seat in front of me is free. I invite him to sit down. He does not seem very well and is dressed in a poor manner. I discover he has a splint on his left leg and seems a bit wounded. From time to time he falls asleep. After a while he starts eating a sandwich drawn from a small bag. We start talking together. I learn he was working as a roofer at dismantling an old factory and had an accident which could have killed him: he fell through a rotten floor and his leg was severely injured. He was returning home. After quite a while, he asked me about my profession. After my explaining him, he kept a little bit silent before saying: "I never go to church, but I don't know why".

It's the first time I hear such a statement, instead of the usual one like "you know, pastor, I never go to church, and I can tell you why!". I like the sentence of the injured roofer because it sounds to me as an precious indication that Christianity is not dying out in Europe, although it's probably the only continent in the world where religion plays a relatively small role in people's life, and though the people's longing for God and for inner life do not necessarily lead them to church as an institution. Europe is a quite secularised place where separation or at least a clear distinction between the political and the religious sphere is the common rule to a very large extent.

This is also the way how European political entities like the Council of Europe (CoE) and the European Union (EU) function. They apply a model which is close to what we French call *laïcité*. There is a consensus in Europe that churches and other religious bodies have a role that does not include controlling

the state or the government, seeking to impose their views on society at large, in particular in the field of morals and personal choices. When they try to do this, their voice is not really heard. If they accept to share their views in a non dogmatic way as a view among others, their voice is listened to and even expected, especially in matters like bioethics.

For me this is the best and the right way to be a church and a witness to the Gospel.

What is the link with the theme “Life before birth”?

It is my way to introduce the topic, setting the scene in which ethical issues like those linked to life before birth, are currently dealt with in Europe, and to indicate how churches and church organisations like CEC take part in the debate. Since 1997 CEC is observer at the CDBI of the CoE, which has probably the highest record in this field worldwide. The EU is increasingly dealing with issues linked to bioethics and biotechnology, because of the developments of the common market and technological advances. Through its WG on Bioethics and Biotechnology of which I am the Secretary, the Church and Society of CEC brings its views and positions into the European ethical discussion, e.g. among other issues, on how the human embryo is protected or sometimes used for research purposes.

My presentation will be divided into 3 parts, based on general information, papers of CEC and current reflections within our WG, thus not representing an official position of CEC as far as prenatal and preimplantation diagnosis are concerned:

- the legal status of the embryo in Europe
- the issue of embryonic stem cell research
- prenatal and preimplantation diagnosis

## **The legal status of the embryo**

No European constitutional court grants a real constitutional status to the embryo. However, almost all of them recognise that it has to be protected on the basis of the right to life according to Article 2 of the European Convention on Human Rights which reads: “Everyone’s life shall be protected by law”. In some countries (Ireland, Germany, Spain, Portugal, Italy), the jurisprudence or the constitution extend the right to life to the unborn child. In France, abortion is allowed in certain cases considered as necessary and under given conditions, only because the law underlines the principle that the embryo enjoys a right to be respected from the beginning of life, as a legal guarantee of the principle of dignity. In Austria, on the basis of his analysis of Article 2 of the European Convention, the constitutional judge says that the right to life is only guaranteed after birth. This is also the case in the Charter of fundamental rights of the EU, in which the right to life is granted to the human person and not to the human being. The so called Bioethics Convention of the CoE clearly illustrates the ambiguous debate on the protection of the embryo. The wording of its Article 1 mentioning both “human beings” and “everyone” makes it unclear whether the human embryo is protected as human being or whether there is a space for distinguishing among embryos between those being implanted and those not. It is therefore no surprise if for more many years now the CDBI has been unsuccessfully trying to achieve consensus on an Additional Protocol on the Protection of the Human Embryo.

Since the development of IVF techniques has led to the existence of living human embryos outside the womb of the mother, things have become even more complicated. The status of these in-vitro embryos is much more uncertain and the judges are very prudent in their approach. The issue is the existence of several options for so called “surplus” embryos from IVF: should they be kept frozen indefinitely, or be destroyed after a certain period of time, or implanted in the womb of other women than the biological mother, or used for research.

## **What are the churches' positions?**

The official position of the Holy See is very clear: life starts from the moment of conception. It deserves the fullest respect and protection of its dignity from this very beginning. The Orthodox churches have the same position, though many of them have not yet expressed it in an official document. Churches of Anglican and Protestant traditions have more diverse views, but none of them would say the human embryo deserves no respect and protection at all. The EKD's position in Germany is near to the R.C. and Orthodox churches. Other Protestant churches would accept some degree of instrumentalisation i.e. of use of the human embryo for research for medical purposes, e.g. to find out treatments for so far incurable illnesses like Alzheimer's or Parkinson disease through research on embryonic stem cells.

As a fellowship of Anglican, Orthodox, Protestant and Old Catholic churches in the whole continent, CEC has following position, which is not fully in line with the one of all its member churches. In its Position Paper of 2002, the CSC of CEC states:

“The approach taken in our churches is to allow and encourage open dialogue on these matters, guided by the wisdom of the Bible and the Holy Spirit. For some of us the Church Tradition represented in the canons of Councils and Church Fathers' writings is also an important and authoritative source of inspiration being seen as a rule of faith and Christian life. The task of the churches is to help believers to take their responsibility - both individually and as a community of faith - in following our Lord Jesus Christ in everyday life with the aim of « a good life with and for the others, in structures which are just » (P. Ricoeur). To use some biblical metaphors : Our common calling (diaconia) is to be good stewards in the world, created and redeemed by God, our Father in Jesus Christ, to become a place where life is worth living for all creatures. The task of the Working Group is to be seen in the same perspective.

“Human life, in biblical light, is meant to be human in the full sense of the word. Although life in the biological sense (including genetic information) is a necessary condition for human life, the latter should not be reduced to the former. In other words, a person should not be reduced to her/his genetic make up. Human life is also relational, affective, cultural, spiritual. It may be seen as life basked in god’s love and in that of one’s neighbour.

“Because fertilisation technology can contribute to the well being and happiness of human beings, there is no reason to be a priori against its development and application. There is, however, reason to be very careful, for this technology has to do with the origin of human life and the handling of human embryos. We want to make clear that what has been developed to help childless couples should not automatically be used as a key to open up other research areas. Moreover, childlessness as such is not a conclusive justification for any research whatsoever. In short, a slippery slope is looming which makes the above-mentioned notion of (political) « conscience de limites » very important.

“Concerning the human embryo and foetus, given that a human being is not to be reduced to its DNA, Christian anthropology does not allow a separation of biological and relational aspects. Biological life in itself, isolated from the (relational) context in which it appears and develops, does not have absolute « ontological » significance. That is why speaking about a human embryo as a future child, or a person to be, should take place in a relational context, more specifically in a parental or marital context. However, because of modern technology, it depends (partly) on our decision, whether embryos outside the womb remain embedded in the net of human relationships or not. It is connected to the decision, whether an embryo is transferred into the womb of the future mother and may become a child. This increase of responsibility concerning the beginning of human life asks for clear and careful moral reasoning, in particular in view of the moral status of surplus embryos.

“While we approve in general of medically assisted procreation, we would like to underline that we continue to understand, from a Christian perspective, children as a gift of God and not as a human right. However sad it may be not to have children, human life, in relationship with God and your neighbour, can be fruitful without having children. Fruitfulness in human life can be expressed in many various ways.”

## **Embryonic Stem Cell Research**

In its paper on New Issues in Stem Cells and Regenerative Medicine in 2006, the CSC of CEC says:

“The prospect of using stem cells to provide replacement cells to treat a wide range of otherwise incurable degenerative diseases is a compassionate aim with which most agree. The primary ethical controversy is whether the human embryo can be used as a source for these cells. There is also a major scientific debate on the potential and efficacy of embryonic versus adult stem cells. Among our member churches there are many for whom all research on embryos which causes their destruction is completely unacceptable, as a matter of fundamental principle. Human life is seen as a continuum from conception to death. To destroy an embryo by using it for research is tantamount to the wilful destruction of a human life. For those holding to this view, the ethical case is clear and straightforward. The position is “under no circumstances.” Only adult or cord blood stem cell research is permissible.

Many of our churches do not, however, share this view and consider that the status of the human embryo increases with development, and would allow embryo research under particular circumstances. Some would argue that to use embryos to create stem cells for potentially lifesaving therapies is more justified

than for treating infertility, providing that no other means are possible and that embryos are not used beyond 14 days. This is a “yes, provided ..” position.

Others argue, on the contrary, that to use embryos merely as a source of cells is too instrumental, negating any sense that the human embryo has a special status. To the extent that embryo research is allowed for limited purposes, a measure of instrumentality is accepted, but this does not mean all uses are thereby permitted. Many would therefore object to the creation of embryos for stem cell research, but might reluctantly agree to use of surplus embryos from IVF treatment, given that these would normally be destroyed. This position is “No, unless ...”.

### **Should we research Adult cells, Embryo cells or Both?**

Placental cord blood and many tissues and organs in the adult body also contain stem cells. These stem cells can normally only produce types of cell relevant to that tissue. Some are already used therapeutically, for example bone marrow transplants, but they are often few in numbers and usually restricted to the organ in question. It has, however, been found that under some circumstances some adult stem cells may apparently be induced to turn into other cells – bone marrow into liver cells or nerve cells, for example. It is not clear how repeatable or how widely applicable these findings are, nor if these would produce enough cells to be therapeutically useful. Obtaining bone marrow cells is also a very invasive process. While encouraged by these developments, we caution against making premature claims or reliance on such prospects. Human stem cell research is still a very young science. No one knows how effective *either* adult or embryo cells may prove. Other embryo research seeks to find the chemicals which control cell differentiation, hoping they might be used to transform adult cells directly into any desired cell type without using embryos in future.

A priori, the case for adult and cord blood stem cells as a general source of replacement cells for degenerative diseases is weaker. By definition embryonic

stem cells must be capable of producing all cell types of the human body, whereas adult stem cells are not designed to do this. If only adult cells were researched the risk is that less conditions might be treatable than if both routes were researched. Some of us would advocate pursuing embryo and adult cell research in parallel, with a cross-fertilisation of knowledge, but others of us consider that ethically, only adult cells can be researched, and any limitations duly accepted.

### **Opportunity Costs**

We offer these reflections on a variety of high technology developments of recent science, but as churches we are also acutely aware of the global health context and of the plight of readily treatable disease that afflicts so many millions of our brothers and sisters in the poor countries of the world. We draw attention to concerns that expensive stem cell research may be a luxury of ‘Northern’ lifestyle which expects to live in good health to a good old age. For many of the world’s population, living even a full span of life would be a welcome change to their normal expectations. We ask how far stem cell research is justified while European countries promoting it still have not fulfilled their promises of the percent of their GDP they dedicate to aid and support for healthcare in the developing world.”

### **Embryos from Pre-implantation Genetic Diagnosis (PGD)**

Some scientists consider that surplus PGD embryos offer a much better chance of producing stem cell lines. If one accepts the use of surplus embryos from IVF treatments, it would seem logical also to accept the use of discarded PGD embryos, because use in stem cell research would seem preferable to destruction. With PGD embryos the instrumental element is stronger, however. In IVF, the couple wishes to have babies which they would not otherwise be able to have, and would not intend any embryos for destruction, as such. In PGD

the couple knowingly embarks on a process of creating embryos, some of which they would choose to have destroyed. If accepted, there would need to be very strict conditions to separate the professional staff involved with the PGD procedure from the research group that would use the embryos, especially to ensure that the number of embryos being produced were no more than that reasonably required for the PGD selection.

This last example leads me to the third and last section of my presentation.

## **PND and PGD**

### **Prenatal Diagnosis (PND)**

In case of a spontaneous pregnancy the genetic analysis of foetal cells can be done by taking amniotic liquid (14<sup>th</sup> – 16<sup>th</sup> week) or by biopsy of chorionic villosity (from 10<sup>th</sup> week onwards). This is called Prenatal Diagnosis or PND.

Like every medical intervention, PND must only be proposed on the basis of precise clinical indications. It provides information on the genetic characteristics of the foetus. It gives couples with a risk of transmission of a genetic disease to their descendants the necessary confidence for starting a pregnancy they would not have envisaged without knowing the existence of such a diagnostic means and increases their possibilities of having a child in good health. However, it is possible in several European countries to carry out PND at “the request” of the mother or the parental couple if they need to be reassured about the state of health of their future child.

The wealth of information on the foetus and the possibilities of choice provided by PND “increases the couple’s responsibility who is first confronted with the need to decide whether to ask for the test or not, then to the difficult ethically problematic choice to continue or interrupt the pregnancy in case of an unfavourable result”.

PND raises also other ethical issues linked to uses of the technique leading to eugenic practices, like sex selection or selection of characteristics for no medical reasons, paving the way to possible inadmissible transfer or use of genetic information given by a test, as well as discrimination of disabled persons.

The fact is that there is a widespread consensus regarding generalised PND among health professionals and society at large in developed countries: most women know about the possibility of PND and, in many countries, its costs are covered the state or health insurances. Presently, 30 years after the first clinical use of PND, the number of pregnant women having recourse to amniocentesis or to biopsy of chorionic villosity is estimated at hundred thousands. The rate of abortion in the first case is 0,5% and 1-2% in the second case.

### **Preimplantation Genetic Diagnosis (PGD)**

Here, the situation is different. This technique has only been applied for the last 18 years and its use remains very limited [2] for various reasons: 1) this diagnosis can only be carried out after an In Vitro Fertilisation (IVF), 2) it implies a highly specialised experimental procedure, 3) its application lowers the success rate of IVF from 25% to 10 -15%, its costs are very high and the rate of resulting multiple pregnancies is remarkably high.

PGD clinical application has been first realised in the United Kingdom by Handyside in 1990. It gives the possibility to select IVF embryos according to their genetic characteristics with the aim of avoiding the transfer of those carrying an anomaly into the uterus.

This technique comprises the genetic analysis of one or two cells obtained by biopsy from IV embryos at a very early stage of development (6-10 cells) or of polar globules taken from the impregnated ovule. The DNA extracted from these cells is analysed in order to find the mutation responsible for the chromosomal anomaly or the genetic disease. The embryos not carrying the mutation are then transferred into the uterus of the mother (between 1 and 3 of them).

In 2001, PGD has been used to detect 33 monogenic illnesses (i.e. due to the mutation of a single gene), which can be detected with a rate of error of diagnostic of 1,8%.

## **Further ethical and theological considerations**

### **1. The starting point is about Intentions**

#### *1.1 PND*

There is a large consensus that the method of PND is a helpful new medical achievement in general, and that its ethical estimation depends on its different *intentions*. For example, PND is used to detect diseases which one can treat or correct *in utero*, during the pregnancy. In this case, PND is a very helpful enrichment of medical possibilities. The ethical question arises when PND is used to detect incurable diseases or abnormalities, with the objective of a possible abortion.

#### *1.2 PGD*

The intention of PGD is the *selection* of healthy embryos, especially in case of risk of genetic disease. So we have to discuss the ethical implications of *selection* (see point 3).

### **2. The second point is the status of the embryo**

The ethical discussion is based on the different opinions concerning the *status of a human embryo*. As already said<sup>1</sup>, Protestants have very different points of view in this matter. Like the Orthodox some of them share the view that the life of each human embryo has to be protected, because every human life participates in the human vocation, especially in the image of God. Others affirm that the dignity of the embryo is depending on its development and its relationships. From this point of view, an embryo which isn't accepted into

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some human relationship, or an embryo whose further life may be very difficult due to a disease, may be destroyed. Concerning PND and PGD, Protestants adhering to the first opinion will exclude PND as a preparation for abortion, and exclude the destruction of embryos after PGD, while the others will be much more permissive.

### **3. The third point is selection**

Destroying an embryo because of a disease or a malformation (after PND) or choosing healthy embryos (via PGD) contains a certain gesture of *selection*, because one prefers a “normal child” to the diseased embryo (in gestation or in vitro). As CSC said in a previous document, the problem here is not “eugenics” in the sense of “a deliberate programme to improve a race or species”, but “the intention is to escape misfortune”.<sup>2</sup>

Nevertheless, on the theological level, this kind of selection is a real problem, because the *worth* of human life cannot be defined through the physical or mental constitution, but only through the gracious acceptance by God. Against this background, three arguments may be used:

- One can say that the embryo can be considered as a simple tissue and as a thing, and that the question of worth, dignity and selection is not relevant. But this would be a dubious reification of human life in its beginnings.
- One can argue that the selection is made in view of the future destiny of the child for whom it may be better not to live than to live with a malformation or a serious disease. This argument refers to the Christian neighbour love. But it remains a very controversial argument: On the one hand, it is impossible to predict the quality of life of a future human being; on the other hand, PND is very often used to detect diseases which generally do not hinder a good human life (like Down syndrome). That is why this argument needs to be completed by a reflection concerning the criteria of selection. Any possible list of diseases

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<sup>2</sup> See the CEC paper: Genetic testing and predictive medicine, 2003.

justifying PND/PGD should be very restrictive, in order to inhibit the destruction of embryos because of minor problems of malformation or disease.

– The third argument concerns a conflict between the interests of the future child and the interests of the mother / the parents. In this perspective, the burden of being responsible of caring for a diseased child may outweigh the interests of the future human being. The discussion of this argument coincides with that about abortion in general.

So what can we say? Some Protestant and orthodox Christians think that we should not create situations which lead us to a choice between several human lives. This is why they are against the creation of “surplus embryos” (and thus against PGD). For others, this choice is possible and requires our human responsibility: If we are able to choose, we have to do so. To choose is better than to leave things to chance. In this case, we have to fix criteria for a reasonable application of PGD. I shall come back to this.

Concerning PGD, there is another question about selection: PGD may allow not only *negative* selection, but also *positive* selection, e. g. in order to cure another child of the family through umbilical blood. I shall come back to this point too.

#### **4. The 4<sup>th</sup> point concerns social pressure and the “perfect child”**

The scientific community and most of the international organisations think PGD should not be allowed except for the couples at risk of giving birth to a child with a serious genetic disease. However the concept of risk and degree of gravity may pose difficult problems of evaluation because many genetic illnesses develop in different and unpredictable ways which depend not only on the genotype, but also on epigenetic and environmental factors.

In the face of a difficult choice which consequences have a major importance for future life, it is essential that the person’s choice is free, autonomous and based on a really informed consent. It is also essential that a non directive genetic

counselling and appropriate to the nature of the test and its implications be an integral part of the PGD process.

The aim of the genetic counselling by professional teams in genetic services is *to inform* the persons who have to choose whether or not they want PGD, *to offer a support* before, during and after the testing, *to communicate the results* in translating scientific knowledge in understandable terms for lay people and *to promote* free and autonomous decisions.

There is a large consensus among Protestants and in CEC's previous paper that neither PND/PGD nor the rejection of a diseased embryo should become an *obligation*. The actual extension of generalised PND among health professionals and society as a whole seems to indicate that pregnant women are increasingly under social pressure to "verify" their future child and to consider an abortion in case of disease. This evolution challenges the concept of "informed consent" and of "autonomous decisions". Recent studies show that many women, in a situation of stress and existential uncertainty, are not really able to assume such "autonomous decisions".<sup>3</sup>

As Christians, we would therefore underline the freedom to refuse PND/PGD, and disapprove of any pressure in view of the "perfect child". The wish to have healthy children should not become a *right* or a *duty*. We are worried about the trend in public opinion to favour such a duty. This can have serious consequences, for example in terms health insurance. Will our societies be ready to pay for the needs of "imperfect children"?

We also consider that "counselling in a non directive way" cannot mean that women and couples are left alone with these problems, but that they are also informed about the ethical principals at stake. Churches have an important role in this respect.

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<sup>3</sup> Romain Favre et al., How important is consent in maternal serum screening for Down syndrome in France ? Information and consent evaluation in maternal serum screening for Down syndrome : a French study, in : Prenat Diagn2007 ; 27 : 197–205.

## **Some specific questions relating to PND or PGD**

### **1. PND and probability**

The rate of abortion linked to PND is between 0,5% and 1-2%. This is a very high risk for a medical procedure of diagnosis, even higher than the risk which the procedure wants to determine (i.e. to have a diseased child). Is the balance of the means respected? This leads us to be very circumspect about a quick and “self-evident” extension of PND.

### **2. IVF/PGD and “surplus embryos”**

In Europe, hundreds of thousands “surplus embryos”, created in the course of IVF/PGD, are kept in refrigerators. If there is no parental project, their only perspective is destruction or being used for research. Irrespective of our different positions concerning the status of a human embryo, we consider that this poses ethical questions. One has to balance the well-being of the women (in case of failure of IVF, surplus embryos permit a second attempt of embryo transfer without going again through the difficult procedure of extraction of egg cells) against the value of human life in itself and against the risk that, in our societies, embryos may be considered as an always available tissue.

### **3. PGD and “drug baby”**

Should we use PGD in order to select an embryo that will be compatible, from an immunologic point of view, with his brother or sister suffering from a serious genetic disease? The main problems, already mentioned, are the possible instrumentalisation of the child, his self-image and the risk that he or she will be asked, during his life, for organ or marrow donation.

In this context, ethicists often quote the categorical imperative of Kant which stipulates that every human being should be treated always “as an end and not simply as a means”. But saying “not simply”, Kant makes clear that every human being is *also* treated as a means. It is clear that the “drug baby” is treated as a means: He or she should help his/her brother/sister. But the main question is whether this child is *also (and primarily)* loved and wanted for what she or he is in herself/himself, and not primarily for the help he or she may bring to the elder child.

The question of self-image is a very complex one: Indeed, the child chosen by PGD may think that he or she lives only because of his or her compatibility with his brother or sister, and this may weaken his or her self-esteem. But, on the other hand, he or she may see himself or herself in the centre of the family solidarity, and this can strengthen his or her position and self-image.<sup>4</sup>

Finally, the risk to be confronted to organ or marrow donation is real. Legal provisions regarding family relations will have to preserve the autonomy of the child, but this will be very difficult in practice. Maybe this is the price to pay if parents choose this way to help their elder child.

#### **4. Extensions of the application of PGD**

The area for application of PGD has been broadened during the last years. The first aim was to obviate serious genetic disease. Today, PGD is also used to select out embryos having only a genetic *predisposition* to some diseases, like for example breast cancer. In these cases, embryos are selected out even if no one knows whether the disease will actually break out. In addition, it is also possible to use PGD in order to detect (and to select out) minor diseases.

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<sup>4</sup> This argument is to be found in the report of the French Ethic Committee on this question (CCNE, avis du 4 juillet 2002).

One may see here a “slippery slope” which leads us to the idea of the “perfect child”. What would be wrong with this? The main problem is perhaps not the selection of the “perfect child”, but the fact that the others are selected out because of their “imperfectness”. Apart from that, probably most people intuitively refuse a more and more sophisticated procedure of selection. The reason for that is that human life always should maintain something which is not available or disposable for human beings and their plans and programmes. No one wants to be only the fruit of human design.

If our societies allow for PGD (which is the case in many European countries), they have to fix criteria to limit its application. We don’t think that these decisions should be left only to the parents. In practice, the definition of these criteria will be difficult and will necessitate a large debate in our societies. Christian churches, if they don’t refuse PGD in general, will opt here for strong limitations of application.

## **5. Perception of what is being human**

All these issues lead to a more fundamental question: What is our vision of ourselves, of the human being in general, and of our offspring?

Do we still believe that “children are a gift from God” (Ps 127,3)? This biblical quote should not lead us to refuse our human responsibility in the area of procreation. But perhaps this statement of the psalm says something about the ultimate ground of our human existence: Our life is a gift which surpasses all human capacities. To see it as a gift of the Creator and not as a product of ourselves (or of our parents), is perhaps the most important perspective of our existence we can have.

## **Some concluding remarks**

Two main complementary principles and convictions should guide policies and practices:

- it is the duty and the honour of society to give responsible support to families who choose to welcome children who will have special needs, and to make a place for those whom life has injured or disabled;
- society should not attempt to provide a substitute for the wishes and inner strength of parents, or impose on parents a choice which is not their own and that they cannot deal with.

The way the community considers and encourages persons with disabilities to take their place in society by developing good inclusion policies is crucial to allow couples to escape any kind of individual, social or societal pressure in their choices provided by PND/PGD.

From a theological point of view, there is a main open question in the case of PGD: Are we allowed to select out human embryos? There is no unanimity, at least in Protestant theology.

The second question is: If the selection of human embryos is admitted, we have to strengthen human responsibility. We humans have to assume this capacity. In this case, we need concrete criteria. But it seems rather difficult to deduce them from theology!

Thank you for your attention.

Richard Fischer

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Strasbourg

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Lecture given to the Anglican and English speaking community.