

23/CNECV/97
Report on
The Draft Bill concerning
MEDICALLY-ASSISTED PROCREATION

(Projecto de Proposta de Lei sobre a Procriação Medicamente Assistida)

by

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"[...] quello che, a nostro parere, andrebbe considerato come il soggetto centrale dell' intero processo di riproduzione assistita, vale a dire il bambino, soggetto, peraltro, piuttosto trascurato dalla letteratura in tema di procreatica."

In: La Fecondazione Assistita.

Documenti del Comitato Nazionale per la Bioetica.

Presidenza del Consiglio dei Ministri, Dipartimento per l'Informazione e l'Editoria, 1995, p. 57⁽¹⁾

I

INTRODUCTION

So as not to extend unduly this report, which I had the honour to elaborate by incumbency of the Portuguese National Council of Ethics for the Life Sciences (Conselho Nacional de Ética para as Ciências da Vida - hereinafter CNECV), I shall consider especially those clauses in the Draft Bill on Medically-Assisted Procreation (hereinafter MAP) that diverge from Report-Opinion 3/CNECV/93, issued on the 10th of February. The clauses referred to are those that allow:

- a) the donation of semen and of oocytes;
- b) the possibility of surplus embryos being allocated to a different couple;
- c) the inclusion of MAP in the medical care provided by the National Health Service.

Some other clauses will also be addressed and, to round off the report, two passages in the Draft Bill's preamble will be commented.

¹ JHN: "... the one who, in our view, ought to be considered as the central subject of the whole process of assisted reproduction, that is to say the baby, [is] on the contrary, a subject most overlooked by the literature on the theme of procreation science." in Assisted Fecundation. Documents by the National Committee of Bioethics, Presidency of the Ministerial Cabinet, Information and Publications Department, 1995, p.57.

The attitude underlying the ethical reflection produced in the present report is one that accords eminent dignity and utmost social importance to human procreation, hence one that attributes inalienable responsibility for it to the parents, society and the State.

From this attitude five fundamental beliefs result:

- a) infertility is not a run-of-the-mill affliction;
- b) its growing incidence, set in the context of a progressive reduction of natality among fertile couples, makes it a worrying national problem – especially important to its solution is prevention based on the (still very inadequate) knowledge of the causes of infertility, requiring research which it is urgent to promote;
- c) medical interventions aiming at procreation must not be determined by the purpose of resolving psychological problems in either member of the infertile couple, for the generation of a child – a subject in its own right – must not be viewed as a therapeutic means;
- d) heavy funding by the State to widen access to MAP which is not accompanied by effective measures to overcome the socio-economic impediments to maternity is a logical contradiction, and ethically unacceptable;
- e) the calculation of the investment by the State to finance access to MAP must also take into account the clamouring needs in medical care.

II

ETHICAL REFLECTION

1. Clauses in the Bill divergent from Report-Opinion 3/CNECV/93

1.1 *Legalisation of gamete donation*

Report-Opinion 3/CNECV/93, in p.96, states that "this Council cannot consider heterologous MAR [**Medically-Assisted Reproduction**] to be ethically acceptable" and, further:

- a) "the [Portuguese] Medical Association's National Council of Medical Deontology, on the matter of the creation of MAR, rejected unanimously all donor-based reproduction;
- b) "in 1989, the Resolution by the European Parliament on *in vivo* and *in vitro* artificial fertilisation declared all forms of heterologous reproduction to be undesirable."

The reasons underlying the ethically negative judgment stated in Report-Opinion 3/CNECV/93 are substantial (vd. Appendix 1) and cannot be dismissed lightly.

Nevertheless, one might reconsider the affirmation that there is an "instrumentalisation" of the donor. Does it exist when the donation is true to its meaning, a disinterested giving, out of pure solidarity, giving which is ultimately giving of oneself? Is that act, moreover, "the negation of the donor's procreative self-fulfilment in terms of ethical freedom, transmitting life outside any responsibility to a parental project and to a family context"?

Heterologous MAP radically questions traditional principles, values and concepts relating to the generation of human life, to personal identity and the conditions for its development, as well as to the conjugal relationship and the family community, entailing thereby complex, delicate juridical and social consequences. That is sufficient grounds to acknowledge that the ethical reflection on this technique eminently requires responsibility and dignity, and hence:

- ⇒ freedom of conscience, both reasoning and moral
- ⇒ openness in the analysis of every argument either contrary or in favour
- ⇒ respect for the rights of the eventual new-borns, which must not take second place to, much less be forgotten before the yearnings of sterile couples
- ⇒ wise anticipation of the possible negative consequences
- ⇒ a pondered, fundamented, prudent judgment, always open to a re-appreciation.

In this regard, an excerpt is enclosed (Appendix 2) of the report *État actuel des études conduites par le Comité concernant les dons de gamètes et d'embryons*, by the French Advisory Committee of Ethics for the Life and Health Sciences.²

The arguments advanced in the Draft Bill to legitimate the donation of spermatozoa are based on the implicit premise that sperm banks are inevitable: that they are here and bound to multiply. Given this, it is better to admit their existence and regulate their activity than to attempt an ineffective legal prohibition that will serve only to keep the situation adrift (cf. clandestine abortion), and might lead to the possible and even probable consequences listed in the preamble (p.7, h).

The Draft Bill's preamble makes no reference to the position on this matter of Report-Opinion 3/CNECV/93 – though quoting from it, and giving it a high accolade by saying that "it gave us the definitive statement of the principles that must underlie the practice of Medically-Assisted Procreation". This omission seems to show that no counter-argumentation was discerned.

I agree that "the growing demand for heterologous reproduction cannot be considered a valid argument in its favour" (3/CNECV/93, p.95). Even so, the criterium of the lesser evil does have ethical status. My view in this regard is that only if there is convincing factual proof that "sperm banks" are not erradicable in

² JHN: *Current Situation of the Studies Conducted by the Committee Concerning Donations of Gametes and Embryos*. Vd. Bibliographic References, at the end.

practice will it be preferable to regulate them. Yet the preamble to the Draft Bill does not proffer any such justification.

From my point of view, denying the person so conceived the right to know both parents is reason enough to reject heterologous MAP.

Indeed, it is admitted that persons so conceived "**may**" obtain knowledge of the donor's identity, but only "**due to reasons of weight endorsed by a Court order**" (Art.12, §3). Still, this clause merely raises a possibility, seemingly exceptional, and meeting it depends on undefined criteria – wanting to know who is your "genetic" parent: is that not, in itself, already a reason of weight?

Knowing our parents' identity is part of our personal historicity, and so of our unique identity, wherefore access to this knowledge must not be denied to anyone; a Court injunction can properly guarantee it but never assess its legitimacy.

Actually, the first of the recognised rights in Art.26, §1 of the Constitution of the Portuguese Republic is precisely that to "personal identity".

This right of anyone to know who are his/her parents is recognised by Germany, Austria, Sweden and Switzerland³ (at least). And, in the preamble to the European Parliament's 1989 Resolution on *in vivo* and *in vitro* artificial fertilisation, one of the rights of babies safeguarded is "the right to a genetic identity".⁴

On the other hand, one must bear in mind the possibility of the occurrence, in the medium or long run, of grievous consequences for the couple and/or the person born; only systematic, reliable studies will permit drawing conclusions in this regard.

Actually, the donor's anonymity and the non disclosure by the couple to children so conceived of the manner of their conception are two of the most debated issues world-wide with regard to heterologous MAP.

One argument that does not hold is that compliance with this right will lead to inexistence of semen donors. Firstly because, in the issue at stake, that is a secondary consideration; second, because experience in Sweden demonstrates the opposite – after some years of decline (the ruling dates back to 1985), donors have increased and are now of a different ethical quality, i.e. they are genuine "givers".⁵

One last consideration, regarding **semen donation**.

The legislation resulting from this Draft Bill will only show its effect towards the end of 1998, at best, for there are several decree-laws to be published within 180 days after its approval (Art. 35), followed by the processing of the applications and the licensing of successful candidates to practice MAP techniques (Art.3, §1). Quite possibly, by the date such authorisations are granted, semen donation will have become unnecessary. In fact, the results already achieved systematically, in many countries, with the intracytoplasmatic injection of a spermatozoon (even an immature one, from the epididymis or even from the testicle) and even of its precursor, the

³ Conseil de l'Europe: *Assistance médicale à la procréation et protection de l'embryon human. Étude comparative sur la situation dans 39 pays*, CDBI-CO-GT3(96) 7ème Rév.

⁴ Cit. in *Report-Opinion 3/CNECV/93*, p. 89.

⁵ F.Shenfield and S. J. Steele: *What are the effects of anonymity and secrecy on the welfare of the child in gamete donation?* Human Reproduction 12: 392-395, 1997.

spermatid, make it foreseeable that resorting to semen donors will become practically unnecessary in the near future.⁶

Nonetheless, **should the law eventually enacted permit semen donation, it must provide for:**

- a) sanctions for non compliance with what is laid down in §1 of Article 15 (the Draft Bill does not address this);
- b) sanctions for semen donation that is not absolutely free of charge (the Bill does not mention this, either);
- c) unequivocal and unconditional acknowledgement of the right of persons generated with donated semen to have access to the donor's identification;
- d) an imposition that any donor be restricted to donations at one establishment only;
- e) an indication of the maximum number of children that may be generated by the same semen donor;⁷
- f) the stipulation that "Semen Conservation Units" [Unidades de Conservação de Sémén] may only exist within public establishments and non-profit private establishments.⁸

Oocyte donation has its own specificities – technical (invasive method) and biological (q.v. Appendix 3: the position taken by the French National Advisory Committee of Ethics for the Life Sciences) – which, in my view, recommend that, at least for the time being, it should not be legalised.

Actually, several European countries that allow semen donation prohibit oocyte donation (Germany, Slovenia, Iceland, Norway, Sweden and Switzerland).⁹

I end this ethical reflection on heterologous MAP with the following question: with the escalation of the increasing genetic/social dissociation of offspring generation (vd. Appendix 4), will we not end up accepting the extreme of cloning?

1.2. **The possibility of surplus embryos being allocated to a different couple**

The ruling that *in vitro* fecundation (IVF) must not give rise to the creation of surplus embryos (Art.20, §1) and that, should they be produced due to unforeseeable circumstances, it is prohibited to destroy them or to use them for research purposes, allowing only that they be frozen for use in the same couple in (a) later cycle(s), is in line with the view expressed in Report-Opinion 3/CNECV/93. The only divergence as to the fate of the embryos is that the latter document disagrees with the transfer of embryos to another couple, while the Draft Bill admits this as a last resort, i.e. in case the couple is unable or unwilling to accept the embryos and consents to the transfer.

⁶ G.D. Palermo, L.T. Colombero, G.L. Schattman et al: *Evolution of pregnancies and initial follow-up of new borns delivered after intracytoplasmic sperm injection*. Journal of the American Medical Association 276: pp. 1893-1897, December 18, 1996.

⁷ France 5, Spain 6, Switzerland 8, Holland and United Kingdom 10. In: Publication cit. in note 4..

⁸ J. Lansac: *French law concerning medically assisted reproduction*. Human Reproduction 11:1843-1847, 1996

⁹ Publication cit. in note 4.

I endorse as correct this provision in the Draft Bill, which makes possible a pre-natal adoption and thus an affective bond between the couple and the child that is probably deeper than would be the case in post-natal adoption. Actually, excluding this possibility would leave only an inglorious frozen conservation *ad aeternum*!

What in my view is unacceptable, on the grounds presented regarding gamete donation, is not giving to the person thus generated the unrestricted right to know his/her parents. In this case, the reasons are even more forceful, since neither the social father nor the social mother are actual parents.

I must also point out a terminology fault in Art.12, §2. While it is correct to say "gamete donation", to say "embryo donation" is not: even if it is considered that embryos are not yet true human beings, it must be conceded that they are so at least potentially, hence not things one owns that may be given to someone else.

1.3. Inclusion of MAP in medical care provided by the National Health Service.

With the exclusion of *in vivo* insemination, MAP techniques are very expensive.

A WHO document ¹⁰ states in this respect that:

“Evaluation of the direct and indirect costs of IVF and related technologies is an essential part of rational planning. To calculate the costs of one IVF birth, one must include the costs of drugs, materials and human resources for all treatment cycles, successful and failed, for all women enrolled in the programme. IVF pregnancies require more high-risk obstetrical care and IVF babies more often require neonatal intensive care, so the costs of these services must be included as well. The proportion of the overall costs of IVF paid by government sources, private insurance sources and out-of-pocket payments by clients should also be determined. IVF costs then need to be compared with the costs of other forms of infertility care, both medical and social.”

“ [...] Following this, the public and the policy-makers decide on the priority to be given to each option, social and medical, for the management of infertility. This allows the appropriate proportion of the resources for infertility to be allocated to prevention (research and services), social options (research and services), conventional medical and surgical options (research and services), and IVF and related technologies (research and services).”

One must also take into account the low rate of success (number of live births per 100 treated cycles), which entails a very high cost/benefit relation.

There is no question of the incommensurable value of the birth of a single human being, but one must not underestimate, either, the value of persons existing already. And, while it is certain that the natality rate has been falling continuously in Portugal, it is equally true that is largely a result of many couples not having the economic means that would allow them to raise the children they would have.

Now:

- a) there is no estimate of the costs entailed by integration of MAP into the National Health Service;

¹⁰ Consultation on the Place of *in vitro* Fertilization in Infertility Care, Summary Report, EUR/ICP/MCH/122(S)7139r, Copenhagen, 1990.

- b) there are glaring insufficiencies in the opportune and qualified rendering of some unquestionably priority health care services;
- c) contraception (even in the form of a voluntary interruption of pregnancy) often results from the economic impossibility of having (raising and educating) children otherwise desired;
- d) expenditure on health is accelerating and out of control ("public expenditure on health is clearly skidding" ¹¹), and it is public knowledge that the Government is concerned with the capacity of the National Budget to keep on supporting health care services without contribution by the users (either direct or through private insurance).

Therefore, I reiterate what is defended in Report-Opinion 3/CNECV/93 (p.100):

"Any up-to-date answer regarding the socially integrated introduction of MAR [medically-assisted reproduction] among us, ought to be produced only in the context of a global, justified and in-depth study, which must be elaborated, of the social cost participation to be allocated to each of the various types of medical intervention."

Already in 1985, the Medical Association's National Council of Medical Deontology had defended, when the creation of MAR centres was envisaged, that:

"in a country where glaring wants and insufficiencies in the health sector await just and adequate solutions, the investment required by the creation of the said centres should be considered non priority." ¹²

In Opinion 14/CNECV/95, from the 4th of October, there is an ample exposition of the great question of the ethical criteria to be used in the allocation and application of resources in the health sector. It is urgent to mobilise national and local government bodies, social institutions and every Portuguese into this question.

Having said all this, I regard as premature the commitment made in Art.14, §2; at most, the eventual possibility may be admitted, provided it is seen to be feasible and its costs are participated by the beneficiaries according to their income.

This is a position I assume against my grain, for it will deny to some what others, by footing the bill, will obtain; it is all the more against my grain because there are still no signs of remission in the shocking ulcer of tax evasion and fraud.

2. Other questions

2.1. Article 4, § 2

As a rule, after a certain age, parents are not in a condition to provide to their children the support they need for their development (from that point of view, the onset of menopause prevents the situation). Furthermore, after the age of 40, the chances of MAP being successful are slim.

Having in mind the interests of the child to be born and also pursuant to what is laid down in subparagraph a) of Art.9 ("the beneficiaries have the right: a) not to be submitted to techniques that do not offer reasonable probability of success"), it would

¹¹ *Opções para um Debate Nacional*. Conselho de Reflexão para a Saúde, Ministry of Health, p. 31.

¹² Cit. in the *Report-Opinion on Medically-Assisted Reproduction (3/CNECV/93)*, p. 99.

be preferable to indicate, in §2 of Art.4, the age limit beyond which MAP is not to be allowed (this is the case, as regards women, in Holland, Hungary and Iceland).¹³ Actually, §2 of Art.28 lays down, with respect to embryos to be transferred to a different couple, that the woman's age must not exceed 45 and the man's 55.

A WHO document recommends pointedly that the age-limit for women be 40.¹⁴

2.2 **Article 8**

The preamble to the Draft Bill (subparagraph h in p.5) affirms that "the resource to Medically-Assisted Procreation must guarantee the child conditions for its integral development."

In some countries, the law provides expressly for the interests of the child to be taken into consideration in deciding access to MAP: this is the case in Cyprus, Ireland, Holland and the United Kingdom; in the USA, the legislations of many states regard the interests of the child as the foremost criterium to be considered, and in Australia the law of 1988 lays down those interests must be held to have foremost importance.¹⁵ In the United Kingdom, the Human Fertilisation and Embriology Act of 1990 rules that not only the child who may be born must be considered but also "any other child who may be affected by the birth".¹⁶

Subparagraph h) in page 5 of the preamble, already referred, indicates as a condition that must be especially considered to guarantee the child's integral development "the right to benefit from the bi-parental family structure of filiation", so that "only heterosexual couples, having a stable relationship, may be allowed to benefit from Medically-Assisted Procreation techniques." This requirement is expressed in Art.4, §1. In my view, this should be taken further, by renumbering §§ 2 and 3 of Art.8 as §§ 3 and 4, respectively, and introducing as §2 a clause inspired in the European Parliament's recommendation on the rights and interests of the child.¹⁷

2.3 **Article 9**

A subparagraph should be added, providing for psychological follow-up of the couple.

¹³ Publication cit. in note 4.

¹⁴ Publication cit. in note 11.

¹⁵ Publication cit. in note 4.

¹⁶ Mark Salmon: *The Human Fertilisation and Embryology Authority and the Law*, p. 3. in "Third Symposium on Bioethics: Medically Assisted Procreation and the Protection of the Human Embryo". Strasbourg 15-18 December 1996. Council of Europe CDBI/SPK(96)23.

¹⁷ Reproduced in *Report-Opinion 3/CNECV/93*, p. 89.

2.4 **Article 9, subparagraph c)**

Pursuant to a document by the Council of Europe on MAP,¹⁸ the following text is preferable:

c) to be adequately informed and receive due advice as to the eventual implications – medical, juridical and social and, if necessary, genetic – of the proposed treatment, especially as regards those techniques that may affect the interests of the child to be born.

2.5 **Article 14, §1**

There are indirect forms of material retribution that the present text does not foresee. It must be laid down unambiguously that any form of retribution is prohibited; the only reimbursement allowed is compensation for loss of salary, for expenses incurred with transportation and others incurred as a direct result of gamete donation or the transfer of surplus embryos to a different couple.

2.6 **Article 20, §2**

The European Society of Human Reproduction and Embryology recommends 3 as the maximum number of embryos to be transferred to the uterus, in one and the same cycle;¹⁹ that is the procedure in Germany, Denmark, Hungary, the United Kingdom and Sweden,²⁰ and that is the recommendation of the WHO.

The aim is to reduce the pre- and post-natal risks of multiple pregnancy and to ward off the heavy burdens it often places on couples, which many cannot afford.²¹

2.7 **Decrees-law and legal instruments provided for**

The necessity for the decrees-law provided for in §3 of Art.15 and in §3 of Art.26 will depend in either case, obviously, on the legalisation of semen donation and of oocyte donation.

The decree-law referred in Art.13 carries extremely important ethical implications.

The highest relevance, from the medical, social, juridical and ethical perspectives, must be accorded to the set of requirements based on which the Minister of Health will authorise the practice of MAP techniques (§1 of Art.3).

That authorisation must be granted for a limited period (5 years in France), renewable by an express, justified decision.

¹⁸ Conseil de l'Europe: *Procreation artificielle humaine*. ISBN 92-871-1675, Strasbourg 1989, Principle 4.2.

¹⁹ Publication cit. in note 11.

²⁰ Publication cit. in note 4.

²¹ I. Johnston: *Some Australian perspectives on in vitro fertilization*. Human Reproduction 11, Suppl 1: 25-27, 1996.

As for the periodic evaluation of quality, it must entail the elaboration by the physician in charge of yearly reports, containing objective answers to legally defined questions, concerning especially all the cycles in which MAP techniques are practiced. The report and evaluation must be published.

The entity charged with the appreciation of the reports and with carrying out the periodic evaluations must be multidisciplinary and widely representative in its composition (obviously, it must not include the parties under evaluation).

Appendix 5 lists the membership of the Human Fertilisation and Embriology Authority (HFEA) of the United Kingdom, called for in the Human Fertilisation and Embriology Act approved by Parliament in 1990 (HFEA began its functions that same year). Pursuant to that Act, HFEA's President, Vice-President and at least half of its members (21 in total) may not be medical doctors or biomedical scientists.

Of course, the entity referred to must have available every indispensable logistic means.

2.8 Revision of the Law

The scientific and technical advances in the field of reproduction, the results of more reliable studies of both the positive and adverse consequences of MAP (especially, regarding the latter: rates of failure, maternal mortality, multiple pregnancies, premature births, low weight at birth, pre- and neonatal mortality of the children and eventual alterations in their somatic and psychic development as well as in their behaviour at least up to adolescence), and an ever more thorough ethical reflection consequent on those processes and results, justify the addition of a last article providing for revision of the Law at the end of a given period (5 years?).

2.9 The Preamble

What is affirmed in paragraph 2 remains obscure, at least to me, for I do not know the "known reasons, of a diverse nature" whereby "adoption, as an alternative method for such couples, does not always achieve the expected results."

Certainly, there are and there will be always some couples preferring MAP to adoption. But there are others and will be others where the opposite is true. Which group makes, will make, the majority? And will not well-pondered advice to infertile couples ²² result in preference for adoption, which avoids (above all to women, I believe) so much unease, suffering and disappointment?

One thing is certain: the success rate of adoption is far higher than that of MAP...

There are many children awaiting adoption and, paradoxically, there are many couples waiting to adopt children. ²³ The question arises of the sluggishness of the administrative procedure leading to adoption (even so, the waiting time, two years on average, is not inferior to the average waiting time for successful MAP..., a success that in the great majority of cases fails to materialise).

²² It should not be carried out at MAP Centres but be included in primary health care.

²³ There are more than 9,000 children housed at 220 homes and 900 in the care of the Ministry of Justice. The average number of adoptions does not reach 300/year and the number of candidates in waiting lists is about 900. ("Público" newspaper, July 11th, 1997, p.14).

Regarding adoption, the newspapers of the 11th of the current month bear good news: the Government has completed amendments to the laws on adoption that will allow the entire process to last nine months (the same as gestation!), with the parental candidates being able to take their future child home well before that time, as soon as Social Security has approved their application.

Another correction refers to ethics being categorised as "an end in itself" (in the two bottom lines of p.27. Now, that category is attributable, by ontological inherence, only to the human being: the latter justifies ethics, whose role is to contribute to the development and fulfilment of the human being with and for others.²⁴

No better ending could be found to round off this report.

the 29th of July, 1997

The Reporter,
Prof. Joaquim Pinto Machado

²⁴ *Report-Opinion 3/CNECV/93*, p.88.

Bibliographic References:

- Report-Opinion 3/CNECV/93 on *Reprodução Medicamente Assistida*, in Documentação, Vol. I (1991-1993), Presidência do Conselho de Ministros, 2ª edição 1996, pp.94-95, Lisboa; **[there is an English Translation of this Report-Opinion]**
- Comité Consultatif National d'Éthique pour les Sciences de la Vie et de la Santé: *État actuel des études conduites par le Comité concernant les dons de gamètes et d'embryons*, in "Les Avis de 1983 à 1993," pp.263-264 and 264-265;
- Pinto Machado: *Relatório-Parecer sobre Reprodução Medicamente Assistida - Um Comentário*, Boletim da Universidade do Porto, nº 18, pp. 52-53, 1993;
- List of Members of the Human Fertilisation and Embryology Authority;
- Human Fertilisation and Embryology Authority: *Executive Structure*: 6 December 1996;
- Membership of HFEA Committees and Working Groups.

OPINION
ON
THE DRAFT BILL CONCERNING
MEDICALLY-ASSISTED PROCREATION

I

INTRODUCTION

On the 23rd of April last, Her Excellency the Minister of Health requested an Opinion of the National Council of Ethics for the Life Sciences (hereinafter CNECV) concerning a Draft Bill on Medically-Assisted Procreation (hereinafter MAP). On the 25th of last May a new Chapter was forwarded to the Council (V) and, on the 25th of June, the full text, with some alterations and additions.

The issue under appraisal is not unknown to the CNECV, which issued, on the 10th of February, 1993, an extensive *Report-Opinion on Medically-Assisted Reproduction* [Relatório-Parecer sobre a Reprodução Medicamente Assistida] (3/CNECV/93). The contents of that document and the fact that it was elaborated on the Council's own initiative, are expressive of how the CNECV considered imperative even then the existence of normative rules in this respect.

The CNECV is aware that this is a complex, difficult matter. Therefore, the publication of the present Opinion was preceded by careful reflection, based on diverse sources of information, including statements produced by specially invited experts on MAP and other fields.

In its Opinion, the CNECV sought likewise an equilibrium of "effectiveness, prudence and reasonableness" – to quote the preamble to the document under appraisal – in an area where "facility does not hold sway".

This underlying attitude explains the Council's view that the law should include a final article determining its own revision in the medium run.

II OPINION

Considering:

- a) the complexity and diversity of the problems relating to MAP;
- b) the plurality of views regarding the values that must be safeguarded;
- c) the insufficiency of knowledge, both scientific and technical (despite the advances achieved) and of the long-term development of children generated by resorting to MAP;
- d) the aspirations of infertile couples and their suffering for failing to generate descendants;
- e) the rights of women relating to their health and those of children concerning the same and also their integral development;
- f) the imperatives of society as to the allocation of finance resources among the different health care services, according to ethically fundamented priorities;

The National Council of Ethics for the Life Sciences issues the following Opinion:

1. The Draft Bill on medically-assisted procreation is opportune, for it fills a legislative void whose drawbacks are expressed in its preamble.
2. There are various ethical objections to heterologous reproduction that resorts to semen donors. Prominent among them is the absence of an unrestricted acknowledgement of the right of persons to know on demand the identity of their parents, the same applying to persons born in result of embryo transfer. Actually, recent progress in the techniques of intracytoplasmatic microinjection of single spermatozoa may render practically dispensable the resource to semen donation.
3. Should semen donation be legalised and in agreement with the appended Report, the law must provide for:
 - a) sanctions for non compliance with what is laid down in Art.15, §1 (the Draft Bill does not address this);
 - b) sanctions for semen donation that is not absolutely free of charge (the Draft Bill does not mention this, either);
 - c) unequivocal and unconditional acknowledgement of the right of persons generated with donated semen to have access to the donor's identification;

- d) an imposition that any donor be restricted to donations at one establishment only;
 - e) an indication of the maximum number of children that may be generated by the same semen donor;
 - f) a restrictive stipulation that "Semen Conservation Units" [Unidades de Conservação de Sêmen] may only exist within public establishments and non profit private establishments.
4. Regarding the determination of parenthood in cases of heterologous insemination, referred to in Art. 16, paragraphs 2 and 3 should be struck out, since:
- a) § 2 is unnecessary and hurts the privacy of men and women;
 - b) § 3 denies the child the right to have a father, which is ethically unacceptable.
5. The technical and biological specificities of oocyte donation lead us to defend its non legalisation, which, in any case, is in line with the various European countries where semen donation is allowed.
6. From an ethical point of view, the clauses in the Draft Bill concerning the number of oocytes to be inseminated and the fate to be given to the embryos thus obtained are basically correct.
7. The fate of the frozen embryos already in existence must be set down, as stipulated in the Draft Bill.
8. In view of the situation still prevailing of serious insufficiencies in health care services, and recognising that the total expenditure by Social Security and the State Budget on health will perforce be constrained by setting priorities on its financing, it is premature to pledge that MAP will borne by the State.
9. For the reasons expounded in the appended Report, §2 of Art. 4 must indicate the age for the woman above which the transfer of gametes, zygotes or embryos is not permissible.
10. In Art. 8 there must be express mention of the rights of the child with respect to the integral development of his/her personality.
- In the same Article, §3 must be reformulated so as to make it clear that the invocation of conscientious objection does not entail, in any case whatsoever, that its motivation has to be made explicit.
11. Pursuant to the 1989 document by the Council of Europe,²⁵ we recommend the following inclusion in subparagraph c) of Art. 9: "The right to be informed, when that is the case, of the eventual genetic implications of the proposed treatment which may affect the interests of the child to be born."

²⁵ Conseil de l'Europe: *Procreation artificielle humaine*. ISBN 92-871-1675, Strasbourg 1989, Principe 4.2.

12. Paragraph 1 of Art. 14 must set a prohibition on any form of retribution to gamete donors and to couples who give their consent to embryo transfer.
13. Pursuant to the recommendations by the European Society of Human Reproduction and Embryology and by the WHO,²⁶ we suggest that §1 of Art.20 should indicate that no more than three embryos may be transferred in the same cycle.
14. The progressive increase in the incidence of infertility imposes, on ethical grounds as well, that investigations into its causes be carried out, to enable its prevention on a scientific basis.
15. Information and counselling on infertility must be provided, primarily, in the context of family medicine.
16. To prevail over infertility, adoption must be promoted – thus complying with Art.36 of the Constituion of the Portuguese Republic, now reinforced by the revision currently underway – and value must be placed on the overt acceptance of the infertile condition, which opens the way to social solidarity activities.
17. A deadline must be set for public and private centres that already practice MAP to file a report on their activities, since they first started functioning up to the date the law comes into force.
18. The continuous progress in the practice of MAP, the ongoing studies of its effects, as well as the in-depth extension of ethical reflection, make it advisable to add a final Article providing for revision of the law after a defined lapse of time.

Lisbon, the 29th of July, 1997

Luís Archer

President of the National Council of Ethics
for the Life Sciences

²⁶ *Consultation on the Place of in vitro Fertilization in Infertility Care, Summary Report.* EUR/ICP/MCH/122(S)7139r, Copenhagen, 1990.

DECLARATION OF VOTE

1. *Introduction: a step forward in medicine, a step back in humanity?*

The problem of the human nature, in the moving, anguished words of St Augustine's "Confessions" – *Quid ergo sunt, Deus meus? Quae natura sunt?* – has no solution either on the individual psychological plane or on the philosophical plane, _ nor does it make sense in the domain of modern science: "(...) *the conditions of human existence – life itself, natality and mortality, worldliness, plurality, and the earth – can never 'explain' what we are or answer the question of who we are for the simple reason that they never condition us absolutely. This has always been the opinion of philosophy, in distinction from the sciences – anthropology, psychology, biology, etc. (...)*"²⁷

Each individual, each person repeats the Augustinian interrogation - undoubtedly a founding question and an opening onto the world - each individual gives an answer with each option of life, with each decision made. Yet, he ignores that he faces a death threat. The death of identity, of the soul, brought on by the introduction of some biotechnologies (including medically-assisted procreation, MAP), which may deface, uproot and denature human life, unpredictably.

Some authors defend that technological advance is the primordial determinant of historical progress. And it is true that MAP, in its experimental and theoretical facet, is part of one of biology's most beautiful disciplines, the biology of development, a scientific field undergoing great expansion, having invaluable importance for the future of humanity (e.g. in predictive medicine or even interplanetary travel). This is, however, a generic survey of the principal ethical implications of MAP, so that this perspective is not pertinent and, understandably, it will not be treated here.

Even so, a previous word on the scientific attitude, as opposed to the clinical attitude, does seem useful. It is indubitable that the modern sciences owe their immense advancement to the decision to deal with all nature (virtually the entire cosmos) from a truly universal point of view, that is to say from an indifferent point of view, i.e. "... *from an Archimedean standpoint taken, wilfully and explicitly, outside the earth.*"²⁸ But the deepest issue at stake in the biopolitical problematics of the (medical) use of biotechnologies, of which MAP is a prominent outgrowth, is the place of the subject, and this is a philosophical, ethical and clinical problem.

We may say in other words that what is at stake are the conditions and the definition of the natural human qualities (capabilities, in the terminology of Amartya Sen and Martha Nussbaum). In this domain, the universalist and "essentialist" position (which, I conjecture and propose, is the traditional position of medicine) seems to have been adopted by various thinkers and is, perhaps, the most fecund and convenient, for it leads us directly to the roots of the controversy presently introduced by procreation medicine. This is the conviction discernable in the works of Martha Nussbaum. This US philosopher, an eminent Hellenist, suggests a definition of the human being as a set of predicates – a mortal individual, "incarnate", endowed with feelings, having a biography that includes childhood, endowed with practical

²⁷ Hanna Arendt, *The Human Condition*. The Univ. of Chicago Press, 1958, p. 11.

²⁸ *Ibidem*, p. 11.

reason, sentiments of affiliation and sociability, one who plays and has fun, having an individuated and separate existence – all being traits which it would extemporaneous to comment. Let it be noted only that an egalitarian pre-judgment is apparent, which serves as fundament to a principle of analogy that is nomologically relevant. To cut short a tributary argumentation of Nussbaum's investigations, let me say I defend that the debate on MAP or on biopolitics, like the debate on human development in general and on women's life in particular, should be centred on what "(...) *is common to all, rather than on differences (although, as we shall see, it does not neglect these) and to see some capabilities and functions more central, more at the core of human life, than others (...)*." ²⁹

Notoriously, one of the most deleterious effects of MAP is the brutal dissociation of genality/sexuality and of maternity/parenthood, the dissolution of the primal experiences of humanity, to wit, the experience of ways of life associated with procreation, maternity, parenthood, individuation, affiliation. For that very reason, MAP also destroys an age-old cultural legacy, which may lead to suppression of the personal conditions in the *philia politiké*, particularly of individual action as the full and open revelation of subjectivity, of the subject, of the *who*: ³⁰ it erases identity-making, ethnic and religious marks that appeared to be indelible, which in every culture (such as the Judeo-Christian) are represented in exquisite narratives about the origin and history of that society and/or humankind.

Apart from this, MAP has become in several countries an outrageous big business, causing several personalities recently to take an unheard of stand, demanding an inversion of the burden of proof in the context of the application of the new techniques of predictive medicine, genetic engineering or MAP: "(...) *While believing it neither possible nor desirable to attempt to outlaw efforts to enhance human characteristics, we found that considerable wariness and skepticism are in order (...). The burden of proof lies heavily upon those who want to propose and pursue an agenda of human enhancement.*(...)" ³¹

Moreover, MAP raises very complex moral and juridical difficulties, such as the determination of maternity and paternity; the fixation of the locus of accountability; the determination of the type and degree of (il)licitness, of the principle of possession and of the burden of proof. ³²

Also, verifiably, issues that are socially much more relevant, in terms of the individual or of the common good – such as adoption, the situation of orphans, distributive justice, are not studied or even considered with the same attention by the society in general, the media or professionals. The dismal traps of eugenics are hushed. ³³ In a constitutional State such as the Portuguese, at such travails to build itself up, MAP, being an expensive and exceptional technique, does not appear to warrant the continued liberalist benefits of presumed innocence and supposed

²⁹ Nussbaum, *Human Capabilities. Female Human Beings*, in "Women, Culture and Development, A Study of Human Capabilities", 1995, p. 63z.

³⁰ P. Ricoeur, introd. to H. Arendt's, *op.cit.*, p.22.

³¹ *The Goals of Medicine*, Hastings Center Report, Nov-Dec, 1996, p. S15.

³² *Ibidem*, p. S20. In Portuguese, vd. R.V.A. Capelo de Sousa: *Os Direitos da Personalidade*, 1995 (for its definition, see p.93).

³³ R.H.Blanck, A.L. Bonnicksen (Eds). *Medicine Unbound*. 1994.

regulation by the market:³⁴ the entities practicing these techniques of procreation medicine must be evaluated, they must show they respect ethical and deontological values, they must publish guidelines and results, prove they abide by quality standards of excellence. They must show how they prevent or resolve the moral problems they cause (vd. below).

In short: we face an escalation in the manipulation of life, we face the near-absolute control of fecundation and birth by technique and individual volition. As with every scientific and technical advancement, the uses they are put to will determine their adequateness and rightness. The most worrying and serious consequence of MAP, in my view, is its insidious and inevitable destruction of the notion or image of humanity and, along with this, through the hollowing out of the individual person, the destruction of the moral person: there will be no lack of those who will predict that, having lost and abandoned the notion of humanity (a cultural, medical, political notion - problematic, perhaps, but shared), no discourse on the protection of the Rights of Man, no sermon about human dignity can still make sense.

Note: the brief considerations below are oriented (out of intellectual loyalty to the clinical perspective, in the strict sense of the latter) to the primordial interests of the person or couple who seek consultation with a physician about an infertility problem. It will be seen that I do not forget the newborn, but I shall endeavour to keep to an internal approach to the logic of reproduction medicine (working as a Hematologist at the IPOFG,³⁵ I have to request for my patients, at times, services from the area of medically-assisted reproduction – I wish to note this and convey my thanks through Dr. Pedro Sá e Melo).

2. *Out of centre?*

Like moral practical knowledge, medical praxis used to be an art (techné) which took for granted the certainty that "*man may never freely use himself in the same sense that an artisan or an artist may freely use their working material,*" as Maria Luísa Couto Soares puts it, explaining further that "*(...) man does not project himself based on an eidos, on a model of himself, in the same manner that an artist envisions the idea of what he wants to do and then knows how to imprint it on the material (...)*".³⁶

Indeed, as shown by Freud, without an idea of himself, an idea with a past, a present and a future, without a biography and a project (*à la* Sartre), man is not a Self for itself. Once the condition that makes possible an idea of the human has been eliminated, the physician's very activity, in fact all social practice will have lost any meaning, its centre of gravity, its field of action: "*To the same degree that the central hypothesis of totalitarianism rests on 'everything is possible', sensible citizenship and reasonable action must rest on the inverse hypothesis of a constitution of human nature, justified by its capacity to open itself out, to preserve or rebuild a political space (...)*".³⁷ That is to say, to nurture the conditions for communitarian life, without

³⁴ Maura Ryan. Communication to the Congress on "*The Goals of Medicine. Setting New Priorities*". Naples, 20.6.1997.

³⁵ JHN: The Portuguese Institute of Oncology.

³⁶ Couto Soares, *Do conhecimento prático*, 1996 (manual copy; with thanks to the author).

³⁷ P. Ricoeur, introd. to H. Arendt's, op.cit, p.13.

anonymity or indifference, polycentric, translating and reinforcing a dynamic network of relationships.

If there is a centre in the medical act, that must be the centre of the chief existential spheres of life of each subject, when he is sick. It may be proved that the concrete determination, in everyday clinical attendance, of that centre is a primal characteristic trait of medical clinical practice. So much so that the Aristotelian doctrine of virtue (*arête*) feeds the clinical experience: "(...) *Everything is related in the structure of Greek life (especially...) as regards a point so decisive as the Platonic and Aristotelian central theory of man's arête (...). It is not a question, however, of mere analogies (...) but of fusing the entire medical theory of the correct therapeutics of the body with the Socratic theory of the care and correct therapeutics of the soul, so as to constitute a whole superior to both (...).*" So says Jaegger in his magnificent *Paidea*.

I say that by the "seminal artifice" which is artificial insemination, the genuineness of the clinical experience is vitiated, it loses its immediate and founding inter-subjectivity (who is the "patient" here, the subject-object of the medical act: the woman, the man, the newborn, the couple?). The medical act is left without a centre, without a clear objective, without an horizon of intentionality, without a univocal and determinable goal. It is fitting, therefore, to look now into the ultimate goals of Medicine, if only schematically.

3. **The culture and limits of Medicine**

In his Report, Pinto Machado pointedly emphasises that "(...) *the ethical grounds (of MAP) must rest on a concept of the human nature (...).*"³⁸ Daniel Callahan also questions whether anyone can defend and justify limits to the manipulation of human life. He refers two classes of answers: one is based on cost-benefit calculation, the other is principial. The latter seeks "(...) *some intrinsic or inherent standards of appraisal and judgment. This has sometimes taken the form of attempts to define an essence of human nature (...).*"³⁹ But "*man has no 'nature' – nothing of (a) simple or homogeneous being. He is a strange mixture of being and not being. His place lies between these two opposite poles*";⁴⁰ who will dare to write with chisel or to proclaim from a chair of authority the limits of human nature? And yet all of us do realise effortlessly, as Camus says, that "*the true work of art is always in the human measure. It is essentially the one that says 'less'. There is a certain connection between the global experience of an artist and the work that reflects it, between Wilhelm Meister and Goethe's maturity.*"⁴¹

Indeed we live in an epoch in which – due to the magnitude and novelty of the changes he has wrought – never, in whatsoever period of the history of human knowledge, "(...) *has man become (...) more problematic to himself as in our day (...).*"⁴² Care, the alleviation of suffering, the good of the patient are the *raison d'être*

³⁸ Pinto Machado. *Documento de Trabalho sobre o Pedido de Parecer do Ministério da Saúde sobre a Proposta de Lei da Procriação Medicamente Assistida*. 1997, p.9.

³⁹ Daniel Callahan, 1994: *Manipulating Human Life*. In *Medicine Unbound*, p.120.

⁴⁰ E. Cassirer, *Ensaio Sobre O Homem*, 1995, p.22.

⁴¹ A. Camus, *O Mito de Sísifo*, p.122.

⁴² Max Scheler, cit by E. Cassirer in *Ensaio Sobre O Homem*, 1995, p.30.

of medicine; but so are health and the knowledge of all things human. What is human, in all its complexity, contradictions and integrity, knowing that the medical act always involves uncertainty, bifurcation and partiality: "(...) *A decision about a part is always part of a judgement about the whole, because what affects the part affects the whole. In medicine, the whole is the whole patient. (...) There cannot be a 'science of persons' in the same sense in which we have other medical sciences, marked by precise definition and measurement. Twenty-five hundred years ago, Plato called for a 'science of practical deliberation' to balance the counting and measuring of what is presently called a 'natural science'(...).*"⁴³ The risk taken on by whoever changes this state of the art, be it by manipulating how one dies, be it by manipulating how one dies, is enormous, huge, and it necessarily involves showing respect for ethical principles (non maleficence, beneficence, autonomy and equity), abiding by guidelines, accountability, openness to risk and cost-effectiveness analysis, etc. On the other hand, any stand taken with regard to the new reproduction technologies, if taken in good faith, must equate or oppose two fundamentalist attitudes of contrary sign: the demonisation of technique and the "essentialism" of natural maternity.⁴⁴

Deciding which are the limits to the transformation and fragmentation of the human body and spirit (and confronting dialectically the fundamentalist answers) is very difficult; the decision must take into account recent lessons of the debasing of man by man, of the instrumental utilisation of the person, it must bear in mind a consequent and coherent realisation of finitude, which, on the contrary, makes us "*gain awareness of the certain futility of projects for the auto-deification of man and accept that a feasible humanism must be built on the basis of what we are and are able to do. (...) The desire for deification has rendered finitude intolerable (though it is perfectly possible to live with it!). We have expelled it from our consciousness; but that was not enough to destroy it, and so it has returned to us in the infinitely more malefic guise of a discourse by (I do mean 'by') death (...).*"⁴⁵ Hannah Arendt's wise words may contribute to light the path we must follow: "*Under the conditions of a common world, reality is not guaranteed primarily by the 'common nature' of all men who constitute it, but rather by the fact that, differences of position and the resulting variety of perspectives notwithstanding, everybody is always concerned with the same object. If the sameness of the object can no longer be discerned, no common nature of men, least of all the unnatural conformism of a mass society, can prevent the destruction of the common world, which is usually preceded by the destruction of the many aspects in which it presents itself to human plurality. (...) The end of the common world has come when it is seen only under one aspect and is permitted to present itself in only one perspective.*"⁴⁶ Furthermore, private life, the life "*deprived of seeing and hearing the Other, as well as of being seen and heard by someone else*" explains and determines the isolation of each in his/her little realm within the "*Cemitério dos Desejos*" [Cemetery of Desires] (to refer José Gil's "ethnographic" book with this title).

⁴³ E.J.Cassel. *Clinical Incoherence about Persons: The Problem of Persistent Vegetative State*. Ann. Int. Med. 125, 2:147, 1996.

⁴⁴ Anne Donchin (1996), in *J. Medicine and Philosophy*, 221, 5:482 ff.

⁴⁵ F. Gil, *A Filosofia não é da ordem da Cultura*. "Diário de Notícias" newspaper, 8/2/1987, p.IV.

⁴⁶ H. Arendt, op. cit., pp. 57-58.

For all these reasons, there is increasing controversy about the purpose and objectives of present-day medicine.⁴⁷ What were, what are, the founding categories or concepts of medicine? What is the natural order, the sense, the telos of the medical act? Knowing that a clinical decision implies nearly always a disciplined, casuistic confrontation with ambiguity, it is easy to see how great is the temptation to compromise by omission and how frequent is the risk of falling into ambivalence.

4. *Relevant values of medicine*

The most difficult clinical problems always involve understanding, being receptive to someone else (in clinical practice, capacity to listen, a well constructed story), in the uncertainty of the unique and irreversible decision. Basing themselves on Aristotle's ideas about the ethics of virtue and Kant's propositions about the faculty of judgment, several authors have shown that the good and correct action, in moral as in clinical practice, involves a delicate equilibrium between (the knowledge of) general rules and ingeniousness in the perception of particulars. The ethic of the freedom of the infertile person or couple, just as the ethic of the responsibility of the physician who treats them, implies a double reciprocity: the *éthos* or *mores* (normality, always pre-defined by the community) and *éthos* (interiority, conscious action and self-affection).

Decisions in such matters are always tragic decisions. Moral dilemmas and conflicts of interests cannot be eluded. In most cases, the concrete clinical solutions will be casuistic, but based on a casuistics with principles, abiding by guidelines of technical excellence which must always include an opinion by an ethics committee, explicitly guarantee compliance with legal requirements and be filed in a national registry. Yet we know that has not been so, in spite of being called for repeatedly.

Resorting to MAP techniques must never be an alternative method to natural reproduction. Stress must be placed on the duty of all intervening parties to assume responsibilities before their own consciences, medicine and the law. The rules of the art, of quality assurance, of risk assessment, of predictive medicine, and of accreditation must be adhered to scrupulously (and be subjected, as in other forms of maternity, to the appropriate forms of control).

I suggest that the accreditation of centres practicing MAP be annual or biannual and dependent on the assessment of the quality (by internal and external, national and supranational standards) of its practice. Pursuant to the principles of autonomy, responsibility and homologation it must be particularly incumbent on the centres themselves to resolve the ethical and technical problems they themselves engender, e.g. those created by surplus embryos and the issues relating to the development of the infants.

5. *Comments on some practical difficulties*

There are some preliminary questions, not the immediate and exclusive responsibility of the MAP clinicians or technicians, which they must imperatively equate, nevertheless; and there are others of substance, which I shall refer succinctly together with some suggestions that are more practical and topical:

⁴⁷ Vd, among many others, *The Goals of Medicine*, Hastings Center Report, Nov-Dec., 1996.

a. does it make any sense to speak of human nature or of potential person? – is this a medical theme? – even if this is an outmoded problem and concept, what is a pre-embryo? is it the embryo up to 14 days, before the primordial notochord is formed?

b. what is a family, in a society undergoing accelerated mutation, experimenting with new forms of conviviality? for instance, given the present divorce rate, what is the value, what is the function of a restrictive definition? ⁴⁸

c. what standards must be set for the various MAP medical techniques (effectiveness of about 10 successes per 100 cycles)? – can a Centre that performs interventions in less than 50 or 100 cycles/years be considered reliable? – what maximum number of ectopic pregnancies is to be considered as acceptable? three? what about triplets, etc.? ⁴⁹ (the profession itself must urgently define or adopt common criteria and standards)

d. how does one prevent the commercialisation and mercantilisation of these therapies⁵⁰ when there are, in several countries, more and more professionals and institutions who defend the principle of profit in medicine and dispense with any ethical commitment (including at times the deontological rules), especially in the use of state-of-the-art technology?

e. the diverse identification of the "patient": the person, the central object of the medical act, must be reconsidered – since the mother's position is an instrumental, wilful situation, shouldn't the "patient-customer" be the baby to be born, the lost defenseless, dependent body? – the newborn must be guaranteed adequate protection, the right to have a Mother and Father, the right to the truth, etc. – who guarantees these? - who assures these?

f. in the case of "atypical" and "borderline" families, adoption, when seen to be possible, should always be preferred; the MAP centres must remain liable for such decisions and responsible for the clinical follow-up of such families when that is requested; these complex and exceptional medical acts must be performed in collaboration with the family's GP.

g. so long as the present crisis of scarce resources for basic care persists, the public health system will not bear any direct economic burden with the concrete MAP process, wherefore, as an alternative, the health insurance appropriate to the situation will be promoted; on the contrary, the State shall honour its responsibilities to the child or children. ⁵¹

h. in the present state of knowledge, if surplus embryos are indeed inevitable, it is suggested they may be made available after a few (2 or 3?) years; a similar destination must be given to those already in existence.

i. the possibility of preventing an already significant set of family and hereditary diseases raises the question of whether it should be compulsory, prior to MAP, to have them tested and prevented (it falls to the MAP Centres to promote or undertake the appropriate measures).

⁴⁸ D. Sampaio, T. Resina. *Família: Saúde e Doença*. ICGZS, 1994.

⁴⁹ Machel Schibel: *A new era in Reproductive Technology*. NEJM 318,13:828-34,1988.

⁵⁰ Jean Bernard: *De la Biologie à L'Éthique*, 1990.

⁵¹ But for a contrary opinion, cf. Jean Bernard, *op.cit.*, p.104.

j. all purpose of profit from MAP is prohibited; so is all trading in conception by-products (including placenta blood) and in parts of the body.

k. the conflicts of interests must be recorded and declared to the ethics committee, which will make a pronouncement, obviously in the presence of and after hearing the medical team; legitimation must not be entrusted to an "invisible hand", nor argumentation to a virtual "judge", wherefore the decisions taken must be formally justified and minutes must be made of the meetings; the physician (in charge) must in every concrete case remain accountable and the locus of accountability must be determined beforehand.⁵²

l. an *urgent* measure (before the end of 1997?), it would seem, is the listing and publication by the Centres practicing MAP of their activity to date, together with a cost-effectiveness analysis, and making it compulsory for them to forward that publication within a reasonable deadline to the College of the speciality and to the CNECV.

6. **Summary**

Pico della Mirandola, in his *Discourse on Human Dignity*, said that for Evantes the Persian, "(...) *Man does not hold one specific and native image of himself but many, that are strange and adventitious (...)*."⁵³ It is fit to ask, facing the present reduction of success to economic success,⁵⁴ whether any image of the human has endured that might legitimate an ethically demanding medical practice, a practice more turned to the heuristics of the sacred than to market ratings. In this, as in other highly technical fields, it is only dialogically that one has access to the argumentation and at last to conclusions that are practically reasonable. In response to St Augustine's interrogation, I have assumed that "*Man is 'work of an undefined kind'*" who bears the responsibility to perfect his own being (a thesis retrieved by Foucault in *Words and Things*⁵⁵). The clinician, the reproduction medicine specialist, therefore, bears the heavy responsibility of directing his "patients/customers" towards more and better health, to more and greater dignity.

For the reasons above, and keeping in mind these premisses, I vote in favour of Opinion 23/CNECV/97 concerning the Draft Bill on Medically-Assisted Procreation.

Lisbon, the 29th of July, 1997

Dr. Silvério Marques

⁵² *The Goals of Medicine*, p.S20.

⁵³ Pico della Mirandola, *Discurso da Dignidade Humana* (p.55).

⁵⁴ Arendt, *op. cit.*, p.97 ff.

⁵⁵ Pico della Mirandola, *op.cit.*; A. Finkielkraut, *A Humanidade Perdida*, 1997, p.52.

DECLARATION OF VOTE

1. I acknowledge and praise the remarkable work done by Prof. Pinto Machado in the elaboration of Opinion-Report 23/CNECV/97, on the Draft Bill on medically-assisted procreation, requested by the Ministry of Health. His report is the fruit of profound reflection, and of concern with answering some of the difficulties that have emerged from the debate of this complex problem. His setting MAP within the socio-economic context of Portuguese society and, particularly, within the context of the deficient conditions of health care services in Portugal is a most important fact, necessarily sufficient to face legislators with some ethical questions in their function as administrators of national priorities.
2. Nonetheless, I cannot fully endorse the Opinion elaborated by the Council, even though I acknowledge, out of solidarity, my share of responsibility for it.

I abstain, in the first place, on procedural grounds: when the CNECV issues an Opinion of an ethical nature it must confine itself to ethical perspectives and must not conform to the textual organisation of whatsoever legal instrument is submitted to it for ethical appraisal. The juridical articulation of any legal instrument necessarily limits the scope of the principles whose enunciation pertains to the CNECV.

3. That same limitation also causes my abstention regarding the contents of the Opinion. In my view, the CNECV's approach to MAP was excessively medicalised, side-stepping and obscuring thereby the philosophical and psychoanalytical questions raised by MAP, though in fact these were expressed both by members of this Council, namely by Dr.Silvério Marques in his document, and by experts heard by the Council, namely Dr.Coimbra de Matos.
4. By way of example, I shall refer only one of the aspects I regard as fundamental to an ethical judgment on MAP.

All of us wish somehow to prolong our existence through something or someone who will give us ties with the history we shall not experience. To beget children is part of that "fate of immortality" inscribed in human life. The fecundity of life, thus, apparently becomes equivalent to fertility. But it is not so: fecundity contains a large range of possibilities, it is "the multiplied and brilliant life" Sophia ⁵⁶ talks about. To set fertility in the larger framework of fecundity is one of the most important aspects of the inner process of development of one's own sexuality.

Some argue for the "need" to have children, for the "desire" to have children (I think the expression of the "right" to have children has shown already its hollowness). Between the two formulae just quoted there is already a huge difference. "Need" expresses an incompleteness of the person, a non-maturation of the person's individual and finite reality – difficulty in experiencing the person's worth as a unique in itself, independently of the place taken in the chain of generations. It might be added that, in much of the world, such "need" may be of economic nature – the

⁵⁶ JHN: most probably, Sophia de Mello Breyner, a Portuguese poet and writer.

children as assurance of supplementary hands in rural societies, the children as security in old age. What of the “desire” to have children? Where does it spring from? From a response to ancestral myths present in every culture? From the omnipresence in woman's life of the dual relationship, of the fusion with another being that pregnancy allows? From the demiurgic temptation so structuring of Man as a being who has the power to create *ex nihilo*? From the incapacity of each human person to live only with him/herself and with the radical and equal-standing alterity of the other?

I recognise the profound suffering that infertility may induce. Infertility produces a narcissist wound that may engender an unbearable degree of anguish. It is the self as a link in the human chain that is at stake. But a wound of that kind must be treated by the appropriate means – which have to do with renunciation, with the assumption of life itself, with the sublimation (in the Freudian sense) of desire. The process of mourning a forlorn wish to have children is probably a life-long process, for the imagination feeds on the cultural milieu and the latter carries a near-imperative to procreate. It is from a mythical universe that springs the desire to have children. Every religious tradition – and especially those of the Book – regard as axiological the blessing that children represent to the just person. And the saga of the barren woman weaves a constant and paradoxical pattern across those traditions.

Such considerations lead me to assert that sterility is not ultimately a disease but the symptom of a personal state (in some cases, undoubtedly, of a physical nature), often related to an attitude to sexuality, or to the other, or even to an unconscious representation of the fearful responsibility of raising children. Hence, I find it difficult to view simplistically MAP as a cure for that situation; it merely resolves a symptom, the fact of not having a child and suffering because of it. It should be recalled that a child does not automatically transform the mother and father into open, giving, fecund beings – everyday life will readily show this.

And the child to be born through MAP, who is it? To structure itself, it needs to discover the primal scene to connect with. Now, in MAP, what is that scene? How will the child carry through life the knowledge that it was begotten by fragmented acts, whose real features it will gradually grasp? Can those fragments be reconstituted into a primal scene?

Ultimately, the whole issue of MAP will touch the most intimate area of each person's identity, the core of its sexual structure.

I cannot fathom why there is today such facile acceptance of every science and technique and such a hush over those disciplines studying the great discoveries in the psychic structure of the human person. It would be the same as wanting to go on exploring the universe of Physics while limiting Quantum Mechanics to a parenthesis! It would seem that the medicalisation of all human acts is preferred to accepting the knowledge of ourselves. Why? Perhaps because science and technology feed the ascensional myth of progress, while psychoanalytical science addresses us inevitably to our specific limits as individuals and as part of the human condition.

Today, after Einstein and Oppenheimer, it is no longer true that science can always surpass itself. There are frontiers beyond which it is no longer logical to seek other worlds, for there lies the destruction of this world of ours. We are actually immersed deep in the change of paradigm now taking shape for the next millenium, but our illusions recoil from accepting this. Not because reason cannot extend further but because there are values that lie above reason. We have emerged from the

"enlightenment era" not to disparage reason but to find that reason is in communion with a reality of symbolic kind, vaster and more profound.

Lisbon, the 29th of July, 1997

Eng. Maria de Lourdes Pintasilgo

DECLARATION OF VOTE

on the Opinion by the National Council of Ethics for the Life Sciences by request of the Ministry of Health concerning the Draft Bill on Medically-Assisted Procreation

1. I decided to abstain from the final voting on the Opinion for the reasons expounded hereunder in this declaration of vote.

It will be evident that my vote of abstention has no adverse bearing on the great scientific and ethical quality of the Report by Commissioner Prof. Joaquim Pinto Machado Correia da Silva, which will endure as a reference work because of the intelligent form it used to compare the positions taken in the previous Report-Opinion 3/CNECV/93 with the provisions in the Draft Bill under analysis. The exactness of Chapter II – Ethical Reflexion – in the Report by Prof. Joaquim Pinto Machado particularly helped me to formulate my declaration of a vote of abstention.

2. I decided to abstain from voting the Opinion because I can neither approve the whole of it nor must I reject the whole of it.

In effect, I cannot endorse the text of paragraphs 2, 3, 4, or that part of §12 which refers gamete donors. Yet I must not reject, by a negative vote, this Opinion, for I agree with all the remaining clauses.

3. The fundament of my vote of abstention is my impossibility to accept, chiefly from an ethical standpoint but also from a juridical and a social standpoint, the legalisation of a woman's fecundation by sperm that is extraneous to the male intervenient in a joint project of parenthood and conjugality shared by a certain man and a certain woman (Art. 4, §1 of the Draft Bill).

Conjugality precedes parenthood.

In every culture, even those most removed from the Judeo-Christian models prevalent in Europe, there are rules of conjugality which *institute*, which impart status to, the transformation of infatuation into love, in the felicitous expression of Francesco Alberoni, and I quote:

"The project each of us lays out for himself involves the other: it is a life project for the other, too; it is the proposition of what must be the joint goals of both. But certain things cannot be joint goals, being incompatible. Some are slight and may be renounced easily, others can be postponed, others are essential.

The search for what must desired by both involves therefore a continuous making and remaking of projects, a continuous search for other ways. But also a continuous finding of points that must not be renounced, because, if they are not striven for, the love itself loses meaning: those are the points of no return. In the projects that are

made and reshaped, such essential points always appear to us with the bonds that may not be undone and which each must accept to make his or her own.

"Therefore love as an institution also appears as a covenant. And this is constituted around a limit, in the knowledge that not everything is possible, that the impossible exists. Love as an institution is always, therefore, a love that seems different, remote, even odd."

(Francesco Alberoni, *Génesis*. Lisbon, Bertrand Editora, 1990.)

Parenthood is not a founding condition of conjugality. But the conjugal project of a man and a woman, of a certain man and a certain woman, may be structured on fertility in such an intense and comprehensive manner that it may appear, in the couple's eyes, to subsume conjugality itself; as if the conjugal *covenant* – to use Alberoni's expression – did not accept infertility as a limit to the possible.

It is in this situation that infertility appears to the couple as a situation of suffering, so intense that the conjugal covenant, the covenant of loving conjugality, is threatened with rupture.

This suffering, brought before a physician, is *illness*, an infirmity, for which the physician may find a treatment.

Sometimes the affliction of infertility has an organic cause, it is a disease, due to an underlying lesion treatable by a medical or surgical intervention. It is not appropriate, in this declaration of a vote of abstention, to list such situations but I may note in passing what is shown in an article in the *New England Journal of Medicine* of 24.07.97, by Sylvie Marcoux and collaborators - the endometriosis diagnosed in 20 to 68% of women studied for infertility may be treated by laparoscopy and this treatment significantly enhances the possibility of natural fertilisation (NEJM, 337 (4): 217-222, 1997).

Once the treatable organic causes have been excluded, we are left with untreatable forms and idiopathic forms.

For the purposes of this declaration of a vote of abstention, I will stress as untreatable forms the impossibility of obtaining for in vitro fertilisation any spermatozoa capable of fecundating ovules, even with the aid of ICSI; immature gametes though appropriate for intranuclear injection into the oocytes or the situation of total destruction of the spermatogenetic line in the testes; or the absence of testes in the scrotum.

When the male component of the conjugal project has such characteristics, parenthood is impossible.

And it does not become possible by resorting to donor's sperm.

The parental project of a certain man and a certain woman is not the sperm that fecundates, it is the whole human person who assumes the paternity and executes it, at the biological level, by means of the fecundating spermatozoon.

Likewise, in the parental project of a certain man and a certain woman, maternity is not merely the fecundated ovule but the whole female person, with the extremely enriching biological and spiritual transformations of the maternal state which start with fecundation and last all life long.

In the conjugal project these transformations are integrated into the conjugality of this man and this woman.

When the couple accepts the contamination of its personal two-person project, by a third party, regardless of the latter's anonymity, it is legitimate to assert that the conjugality has been broken, thus placing this couple, in fact, outside the conditions laid down in Art.4, §1 of the Government Draft Bill.

Subparagraph h) in the preamble to the Draft Bill "justifies" semen donation with an unacceptable affirmation - the (donation of male gametes) may not be denied when every consequence that may result from that act to the potential "beneficiaries" are fully assumed by the same. It is the same as saying that, if I assume the consequences of being arrested, I may not be denied the right to steal or even to kill.

Now, what is at stake is not the right of a citizen to wish to donate his sperm; what is at stake is the ethical, juridical and social legitimacy of that sperm being applied by the physician to a conjugal project so as to substitute an impossible parenthood.

4. From my point of view, the ethical legitimacy of the practice of medically-assisted reproduction, by physicians, rests exclusively on its being the treatment of some form of suffering, affliction or disease.

At this level, the disease is the infertility of a certain couple and the suffering it causes, in an intense, prolonged manner, to this same couple, to a certain man pursuing a relationship of conjugality with a certain woman.

The use of sperm (or ovules) external to this couple ('third party (!) donor' is the name used in Art.15, §1 of the Draft Bill) generates a triangular relationship that is ethically unacceptable because it falsifies the relationship of conjugality and does not treat the couple's infertility. The couple continues to be infertile, even if the feminine element has accepted an embryo to whose production, *in vitro*, only one of the members of the conjugal couple has contributed.

The adoption of abandoned embryos, as that of children already born and abandoned, must never be seen as a treatment of infertility - it is not limited to infertile couples, either - but as a decision made for the benefit of the embryo or of the child abandoned and under serious threat to its life. To regard it as the contrary would be an instrumentalisation of the embryo or child.

In short: fecundation by means of a donor's sperm or a donor's ovule is not ethically acceptable because it is not a medical act having a therapeutic purpose.

The greatest risk of accepting this medical practice as an ethically acceptable practice is the following: once the medical instrumentalisation of the fertilisation process has been admitted, everything else must be ethically acceptable: the utilisation of ovules from aborted fetuses, the fertilisation of women having no conjugal project, of women in homosexual "conjugality", of women in their menopause or of adolescents capable of being fecundated – so long as they wish it and, as the Draft Bill says, "they assume the full consequences that may result from that act".

The above arguments alone are enough to force me to vote abstention.

Yet I must still consider the implications to the children, the human persons who, in more or less 20 % of the attempts, will result from this fertilisation with a donor's sperm or ovule.

5. From the point of view of the newborn, the implications resulting from an insoluble ambiguity regarding its paternity are also grounds to consider this medical procedure as ethically unacceptable. Let us look at those implications in the different models

5.1 Absolute anonymity of the donor, under penalty of fine and imprisonment to anyone supplying any information about the donor's identity – this being the case of the French law of 1994. Nobody's child, *enfant de personne*, is the name coined by Geneviève de Parseval and Paul Verdier (*Enfant de Personne* – Paris: Odile Jacob, 1994).

This model deprives the person of the knowledge of his/her genetic identity, which is a right acknowledged by the UNESCO Declaration on the human genome and human rights, as will be seen from the following transcription from the original of the Bill prepared by the *International Bioethics Committee*, approved on the 25th of July, 1997 by the Committee of Governmental Experts and certain to be ratified at the General Conference next October:

"Article 1

The human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity. In a symbolic sense it is the heritage of humanity.

Article 2

a) Everyone has a right to respect for their dignity and for their human rights regardless of their genetic characteristics. ..."

It may be argued that if the members of the couple give their consent to the generation of a child by a biologically anonymous father, the child has lost the right to demand knowing its natural father. I transcribe the answer from an article by Anne Mette Maria Lebech, from the Centre for Ethics and Law of the University of Copenhagen, published in the journal "Bioethics" (*Anonymity and informed consent in artificial procreation* – Bioethics 11 (3 e 4): 336-340, 1997): "*children orient themselves in the world by referring their whole being to the part of themselves they think of as masculine - in other words to their origin. They understand themselves in terms of a covenant between their mother and their father, and they seek to clarify their identity by appealing to this cosmic formula. Perhaps they are justified in assuming that this formula, which is their own very personal one, is radically changed by the fact that one of their parents does not belong at all to this hieros-gamos (holy marriage). As this is a question of personal identity, they might feel deeply deceived, and even betrayed in their innermost being, if their parents have hindered their*

symbolic self-understanding in its direct reference to reality and have forced them to live with a lie about their true identity."

In short, the parents do not have the right to lie to a son or daughter about their true identity, starting with their genetic ancestry.

5.2 Identified or identifiable donor.

Although this model respects the right of the child begotten by heterologous in vitro fertilisation to know its biological identity, the problems relating to paternity and to parental responsibilities remain very complex juridically-speaking and demand very detailed legislation (vd. enclosed, *The Regulation of Assisted Conception in England*. Kristina Stern. in the *European Journal of Health Law*, 1: 53-79, 1994), which does not, nevertheless, resolve the initial ethical fault and always give rise to a double paternity which is most disturbing to the child (or adolescent or adult) on the psycho-affective plane. Be it compulsory or only on demand, the communication to the child of the biological identity linked with a stranger to the couple, who may be dead already, or may have turned criminal after the donation, is a factor of great disturbance and its consequences are unpredictable.

The identification at the time of collection, and in the act of insemination or MAP, is compulsory to prevent the risk of incestuous fecundation, but its disclosure to third parties is not, namely to the son or daughter. Notwithstanding this, abuses are on record, among which must be referred the case of one physician who practiced medically-assisted procreation using systematically his own sperm, collected and frozen beforehand.

In both models, anonymous father or identifiable father, a human being is intentionally created, disrespecting two internationally recognised human rights - United Nations Convention on Children's Rights of the 20th of November, 1989 - which are the right to a biological identity and the right to normal development.

We all know that, unfortunately, the latter right is often ignored or overlooked, outside of situations of medically-assisted procreation with gametes external to the couple, so that many so-called normally conceived children suffer grievous development vitiation in the midst of pathological families. But what is at stake here and constitutes an ethical wound is the *intentionality* of the creation of human beings, in which fundamental human rights cannot ever be respected due to the pre-conditions of this intentional creation.

In conclusion: being unable to accept, from an ethical perspective, neither the clauses in the Draft Bill concerning the donation of sperm nor the treatment given to those clauses by the CNECV's Opinion, I abstain from voting on this Opinion, although I pay homage to the great effort to achieve a consensus attested by the Opinion.

Lisbon, the 29th of July, 1997

Prof. Daniel Serrão

Bibliography:

STERN, Kristina, - *The regulation of assisted conception in England*, European Journal of Health Law 1: 53-79, 1994, © Kluwer Academic Publishers, Netherlands, 1994

DECLARATION OF VOTE

In my view MAP is in fact a therapeutic intervention, having precise indications (verified sterility - disease) and I agree with the Report in its entirety, particularly where it refers that it is not the purpose of MAP to solve the psychological problems of either member of the couple. In this regard, the wording of the legal text must not allow semen donation as a technical means to which MAP may resort, since

- a). it does not correspond, medically-speaking, to a cure for sterility, for the latter in fact persists, merely undergoing a cosmetic intervention;
- b). it suffers from the grave ethical fault of introducing a third element into the field of "progenitors": an element which, albeit unknown, is none the less real, silenced within the relationship of the putative parents yet present, for whose existence we may never presume the child's consent;
- c). it is seriously grievous to justice and to the constitutional rights of the individuals thus generated, for it denies their access to knowledge of their biological filiation and thus of their very identity.

Lisbon, the 29th of July, 1997

Prof. Walter Osswald

DECLARATION OF VOTE

I consider that, besides the “objections” against it referred in point 2 of the Opinion, heterologous reproduction, analysed from a philosophical point of view, lacks ethical grounding.

Lisbon, the 29th of July, 1997

Prof. Michel Renaud