

## POSITION STATEMENT

### ***ETHICS AND ASSISTED PROCREATION: Guidelines for the Donation of Gametes and Embryos, Surrogacy and Preimplantation Genetic Diagnosis***

#### LIST OF ERRATA

#### **SUMMARY**

Page xxi, last paragraph before the box, lines 1 and 2, should read: Also, as mentioned in Articles 42 and 44 of the *Act respecting clinical and research activities relating to assisted procreation*...

Page xxix, last line, should read: reason to believe she is under 21 years of age.

#### **CHAPTER 1**

Page 11, footnote 4, line 2, should read: This definition has been borrowed in part from the definition in article 2 (1) of Bill 26...

Page 21, footnote 52, last two lines, should read: Chapter 1.1 (articles 538 to 542 of the C.c.Q.).

Page 23, footnote 69, line 7: read: 1<sup>st</sup> Session, 39<sup>th</sup> Legislature, 2009.

#### **CHAPTER 2**

Page 31, notes 88 and 89: These footnotes should be read together but in reverse order, starting with note 89.

Page 46, paragraph 2, lines 1 and 2, should read: Also, as mentioned in Articles 42 and 44 of the *Act respecting clinical and research activities relating to assisted procreation*...

Page 47, footnote 165, line 1, should read: In Spain, under article 5.5 paragraph 2 of the Law of 2006

Page 47, footnote 165, last line, should read: article 5.5 paragraph 3.

#### **CHAPTER 3**

Page 71: note 238 should conclude with the following reference: *Assisted Human Reproduction Act*, article 3.

Page 72, paragraph 1, line 1, should read: to believe she is under 21 years of age.

Page 73, footnote 243, column 2: the reference to the Human Fertilisation Embryology Authority Code of Practice should read as follows: HFEA, *Code of Practice, op. cit.*, s. 14.

Page 77, note 266 should conclude with the following sentence: However, under such circumstances, the Directeur de l'état civil could investigate in order to complete the act (article 130 of the C.c.Q.)

Page 77, footnote 268, line 4, should read: the ruling in the case of *O.F. c. J.H.* ...

Page 77, footnote 269: this footnote should read as follows: The International Convention on the Rights of the Child was ratified by Canada December 13<sup>th</sup> 1991, entered into force January 12<sup>th</sup> 1992, and guarantees the right of a child temporarily or permanently deprived of his or her family environment to special protection and assistance provided by the State: (art. 20): <http://2.ohchr.org/french/law/crc.htm>.

Page 77, footnote 271, the second part of this footnote should read as follows: This solution would also comply with article 7 of the International Convention on the Rights of the Child, according to which the child, [...] as far as possible, has the right to know and be cared for by his or her parents.

Page 77, footnote 272, last two lines: should read (paragraph 78 of the ruling).

## CHAPTER 4

Page 95, footnote 329, line 10, the reference to provisions of German law should read as follows: [Sections 1(1) and 1(2)].

Page 113, footnote 384, should read: This remark, it should be noted, also applies to other diagnostic techniques such as PND.

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POSITION  
STATEMENT

ETHICS  
AND ASSISTED  
PROCREATION:  
Guidelines for  
the Donation  
of Gametes  
and Embryos,  
Surrogacy and  
Preimplantation  
Genetic  
Diagnosis

SUMMARY AND  
RECOMMENDATIONS



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the masculine is used without  
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MEMBERS OF THE WORKING COMMITTEE	iii	Embryo donation	38
LIST OF ACRONYMS	x	The values at stake	40
SUMMARY AND RECOMMENDATIONS	xiv	Ethical issues	42
INTRODUCTION	4	The development of children resulting from a donation	42
CHAPTER 1: THE CONTEXT OF ASSISTED PROCREATION	10	- Filiation: what importance should be accorded to genetics?	42
From adultery to the desire for a child but also involve risks	12	- The existence of a genetic bond: egg donation and sperm donation	44
Today's techniques are more effective but also involve risks	14	- The absence of a genetic bond: double gamete donation and embryo donation	45
Risks for the physical and psychological health of women and children	16	- Access to origins: should anonymity be lifted or not?	46
Beyond medical indications: the evolution of the concept of the family and its transposition in the legal system	20	- The interests at stake	47
CHAPTER 2: GAMETE AND EMBRYO DONATION: BALANCING THE INTERESTS OF STAKEHOLDERS	26	Respect for the dignity of each human being	50
Clinical practice	26	- The non-commercialization of the human body and its products	50
Sperm donation	28	- Compensation for donors	50
The technique	28	- Indemnities for donors	51
The practice	29	- Reimbursement of expenses	52
- Recipient profiles	29	- The non-instrumentalization of individuals	54
- Donor profiles	30	- The interests at stake for parents	54
- Outcomes	32	- The interests at stake for children	54
Egg donation	32	The supply of gametes for infertile individuals	55
The technique	32	- Directed gamete donation	56
- Egg retrieval	33	- Intragenerational and intergenerational donations	56
- <i>In vitro</i> maturation	33	- Paired donation	58
- Embryo transfer	34	- Shared Donation	58
- Risks associated with treatment	34	- Donation and posthumous insemination	59
- Egg donation programs	34	- Embryo donation	62
The practice	35	Prevention and education: acting before the initial stages of assisted procreation	63
- Recipient profiles	35	CHAPTER 3: SURROGACY: MAINTAINING THE LEGAL STATUS QUO	68
- Donor profiles	37	The legal framework	70
		The context of practice	72
		Ethical issues	74
		The status of the child	75
		The development of the child	78
		Access to origins	80
		Women's health	81
		Women's autonomy	82
		The non-commercialization of the body and the non-instrumentalization of persons	83
		Cross-border reproduction	84

<b>CHAPTER 4: PREIMPLANTATION GENETIC DIAGNOSIS: MONITORING PRACTICE IN ORDER TO AVOID DRIFT</b>	<b>88</b>	<b>APPENDICES</b>	<b>166</b>
The technique: two main objectives	90	Appendix 1 – Semen donor recruitment, screening and testing	166
The regulatory framework	93	Appendix 2 – Canadian statistics for the year 2005	177
General reflections on the use of preimplantation genetic diagnosis	101	Table 1.	
The change in the meaning of assisted procreation	102	Cycle outcomes for the most common types of ART procedures	177
The complexity and risks of the procedure	103	Table 2.	
Innovative character and risk assessment	104	Comparison of singleton and multiple births	178
The values at issue in preimplantation genetic diagnosis	108	Table 3.	
The health and well-being of children	108	Clinical pregnancy and birth outcomes by female age for the three most common ART procedures	179
The dignity of the child	109	Table 4.	
- The non-instrumentalization of the human being	109	Clinical pregnancy rate per embryo transfer procedure and multiple birth rate per known birth by number of embryos transferred in IVF/ICSI cycles	180
- Respect for symbolic freedom	109	Table 5.	
Reproductive autonomy	111	Embryo transfer rate during IVF	181
Equality among people	113	Appendix 3 – Comparative table of authorized assisted procreation practices, by country	182
Practice and ethical issues	115	Appendix 4 – Diagram of gene transmission probabilities	187
Diagnosis aimed at increasing the chances of assisted procreation succeeding	115	Appendix 5 – Medication for IVF	188
Diagnosis aimed at the health of the child	118	THE CONSULTATION ACTIVITIES OF THE COMMISSION AND CONTRACTED RESEARCH WORKS	190
- The diagnosis of monogenic diseases	118	MEMBERS OF THE COMMISSION	192
- The diagnosis of embryos that are heterozygous carriers of genes for a recessive disease	125		
- The diagnosis of susceptibility genes	126		
Diagnosis for the benefit of the health of a third party	127		
Diagnosis for non-medical reasons	132		
- The birth of children with disabilities	132		
- Sex selection	134		
- The choice of specific characteristics	134		
<b>CONCLUSION</b>	<b>138</b>		
<b>GLOSSARY</b>	<b>142</b>		
<b>BIBLIOGRAPHY</b>	<b>150</b>		



## LIST OF ACRONYMS

### **AHRC**

Assisted Human Reproduction Agency of Canada

### **AI**

Artificial insemination

### **AID**

Artificial insemination by donor

### **AIH**

Artificial insemination by husband

### **AP**

Assisted procreation

### **ART**

Assisted reproductive technologies/techniques

### **ASRM**

American Society for Reproductive Medicine

### **C.c.Q.**

Code civil du Québec  
(Quebec Civil Code)

### **CCNE**

Comité consultatif national d'éthique  
pour les sciences de la vie et de la santé  
(National Consultative Committee on Ethics  
for Health and Life Sciences) (France)

### **ESHRE**

European Society of Human Reproduction  
and Embryology

### **FISH**

Fluorescent *in situ* hybridization

### **FSH**

Follicle-stimulating hormone

### **GnRH**

Gonadotropin-releasing hormone

### **hCG**

Human chorionic gonadotropin

### **HFEA**

Human Fertilisation and Embryology Authority  
(United Kingdom)

**HLA**

Human leukocyte antigens

**ICSI**

Intracytoplasmic sperm injection

**INSPQ**

Institut national de santé publique  
(Quebec National Public Health Institute)

**IUI**

Intrauterine insemination

**IVF**

*In vitro* fertilization

**IVM**

*In vitro* maturation

**LH**

Luteinizing hormone

**OHSS**

Ovarian hyperstimulation syndrome

**OS**

Ovarian stimulation

**PCR**

Polymerase chain reaction

**PGD**

Preimplantation genetic diagnosis

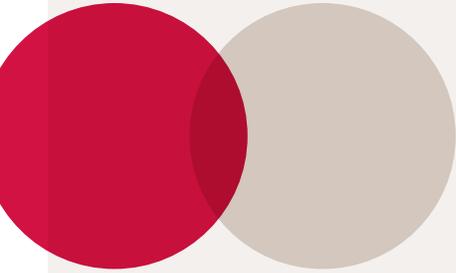
**PND**

Prenatal diagnosis





SUMMARY AND RECOMMENDATIONS



## SUMMARY AND RECOMMENDATIONS

The themes related to the beginning and end of life leave no-one indifferent. Assisted procreation (AP) is no exception to this trend. AP raises passions and provokes debates, probably because it evokes deep feelings and touches a sphere of human life rich in emotional and symbolic values. However, a clear-sighted analysis of ethical issues requires a more detached and more rational view of practices that are current, or could become current in the near future. One of the challenges the Commission has faced in this position statement lies precisely in striking a balance between the heart and reason.

In this position statement, the Commission is conducting a “thorough analysis of the ethical and societal values connected” to AP, in order to address the issues submitted to it by the Minister of Health and Social Services. Given the mandate entrusted to it, the Commission’s thinking has a single aim: namely, to enlarge on work already underway

at the Ministry of Health and Social Services and to present ethical considerations related to three practices: gamete and embryo donation, surrogacy and preimplantation genetic diagnosis (PGD).

From the outset, two preliminary remarks should be made; the Commission has kept them in mind throughout the process leading to production of this position statement. First, the Commission considers that, in addition to AP, the adoption of children is an alternative worth considering, in cases where a person is having difficulties conceiving naturally. In addition, the Commission considers that there is no such thing as a “right to a child,” and as a result the State is not required to satisfy the requests of all citizens where assisted procreation is concerned.

## THE CONTEXT OF ASSISTED PROCREATION

The term “assisted procreation” refers to various forms of support for human reproduction using medical or pharmaceutical technologies, or laboratory manipulations that attempt to overcome problems of infertility in heterosexual couples, or the inability to procreate naturally in the case of homosexual couples or single women. These technologies also allow fertile couples for whom there is a risk of transmitting a serious disease, whether genetic or viral, to try to have children who will not suffer from such a disease.

Assisted procreation includes the following activities: ovarian stimulation, the collection, processing, *in vitro* manipulation and preservation of human gametes, artificial insemination with sperm provided by a spouse or donor, preimplantation genetic diagnosis, and the conservation and transfer of human embryos.

Although these practices are increasingly seen as routine, safe and effective procedures, they are not risk-free. At a more fundamental level, however, assisted procreation has disrupted our symbolic points of reference, our representations of the family and blood relationships, of the child, and of the existence and intrinsic value of the human being.

### **From adultery to the desire for a child or to the right to a child**

In the eighteenth century, experimental biology first explored assisted procreation as a way of overcoming male infertility. Since that time, AP has continued to develop discretely in medical practice. From the outset, using technological means to assist reproduction has raised moral issues, particularly with regard to sexual morality.

The involvement of a third person in the conception of a child could be seen as a form of adultery, and physicians have therefore developed technical measures so that medical practice cannot be equated with morally unacceptable sexual behaviour. The notion of medical indications seems to have made the transition possible between, on the one hand, applications considered socially and morally acceptable and, on the other, applications likely to destabilize social life and an individual's emotional and mental equilibrium.

The notion of medical indications has provided a point of departure for legislators, in setting legal frameworks for the drafting of laws and practice guidelines. This notion is no longer the primary justification for access to assisted reproductive techniques (ART) – actually, access to such techniques is no longer solely related to a diagnosis of infertility, and is now more broadly related to the desire to have a child. Gradually, this desire to have a child has increasingly been transformed into a “right to a child,” which in turn includes the right to use all available means to have a child.

Nowadays, assisted procreation has a recognized and institutionalized place, which has allowed many people to fulfill their desire to have a child. Moreover, it has become a major and highly profitable activity in several countries, and has become widespread in large part due to the development of new technologies, the emergence of new societal values and social change.

### **Today's techniques are more effective but also involve risks**

Clinical assisted procreation activities involve many different kinds of procedures; they depend on the cause of infertility or sterility, which prevents conception of a child, or on the desire to have a child among people who have no fertility problem, but who cannot procreate naturally.

These techniques involve several risks. The most important risk is multiple pregnancy, which constitutes a risk for the health of mothers, fetuses and the unborn, regardless of the reproductive technique used. Other risks include those associated with ovarian stimulation, with stress and the frustration that accompany such a complex technology, psychological risks resulting from an inability to procreate, as well as risks for children (these latter have been poorly documented to date).

## **Beyond medical indications: the evolution of the concept of the family and its transposition in the legal system**

To better understand the general trends affecting the means by which a society reproduces itself, we must first inquire into the characteristics which a family needs in order to be regarded as such within a community or group. Currently, the traditional nuclear family (man, woman and children) is no longer the only socially accepted model, although it remains nevertheless the dominant model.

However, since 2002 assisted procreation has become a real prospect for single women or homosexual couples who want a child without resorting to adoption, while being biologically related to the child and although they do not themselves have a fertility problem. It is now possible to consider assisted procreation as a means for establishing a filial bond that is both full and autonomous.

In terms of the legal framework for AP, the federal Parliament of Canada passed the *Act respecting assisted human reproduction and related research* in March 2004. This law prohibits a number of practices and establishes the legal framework for activities considered legal. In December 2004, the Quebec government referred the constitutionality of this federal law to the Court of Appeal of Quebec on the grounds that it went beyond the legislative competence of the Parliament of Canada and encroached on the power of the provinces to legislate in matters of health. The Court of Appeal struck down the provisions contained in the reference. The federal government has appealed to the Supreme Court of Canada, however, to determine which level of government actually has power to legislate in this area.

Moreover, in April 2009 the Quebec Minister of Health and Social Services introduced a bill to regulate clinical activities and research in the area of assisted procreation. This bill was adopted by the National Assembly. The *Act respecting clinical and research activities relating to assisted procreation* received assent on June 19, 2009.

The elements outlined above highlight the fact that the development of assisted reproductive techniques available in Quebec is not the only factor that can explain the recent surge in the use of AP; a series of factors emerging over the last few years has also contributed to the situation. The development of medical practice raises questions about such important aspects as the social representation of filiation; the desire to protect those persons relying on assisted procreation and the children born as a result requires thorough ethical reflection in order to guide the actions of stakeholders. The first issue addressed by the Commission in this regard concerns gamete and embryo donation.

## **GAMETE AND EMBRYO DONATION: BALANCING THE INTERESTS OF STAKEHOLDERS**

The Commission has focused on clinical practice and its implications for third-party contribution to parental project, in order to better understand the issues and values underlying this participation.

### **Clinical practice**

When resorting to a third-party contribution to the parental project, infertile people must meet a number of requirements which have several similarities. Gamete donors and women receiving donated sperm or eggs must first undergo basic medical examinations in order to assess the health of the persons involved. In addition to medical assessments, psychosocial assessments are also made, and women recipients must complete a consent form that provides important information about the proposed technique.

### **Sperm donation**

The change in practices surrounding insemination with donor sperm is largely related to the development of semen conservation techniques. Actually, at room temperature fresh semen can only be conserved for one hour. However, sperm can now be frozen indefinitely in liquid nitrogen using a technique called cryopreservation. This technique has led to the establishment of sperm banks.

Artificial insemination (AI) refers to all forms of insemination undertaken without sexual intercourse. There are three main categories of AI, depending on whether sperm is fresh, is supplied by the spouse or by a donor.

### **Recipient profiles**

Clinics enable people whose infertility is medically proven to gain access to donated sperm. Heterosexual couples, single women and lesbian couples have access to such donations.

In 2007, according to data obtained by the Commission from one of the clinics consulted, about 50% of donated sperm was used to alleviate a medical indication or unexplained infertility. The remainder of donated sperm went to women who had applied for it on social or personal grounds (about 40% were homosexual women and 10% were single women).

### **Donor profiles**

Potential donors must be between 18 and 40 years of age, have a stable sexual life (with only one sexual partner during the previous six months), be in good physical and mental health, and know the identity of their biological parents so their medical history can be determined.

### **Outcomes**

In Quebec, a single clinic was consulted which runs a sperm bank and distributes sperm through fertility clinics in the province. This clinic estimated that over the last ten years, 1,600 children were born as a result of donated sperm. The vast majority of these donations were used in artificial insemination programs (98%) rather than in *in vitro* fertilization (IVF) programs (only 2%). The clinics consulted indicate that assisted reproductive techniques using sperm donation obtain substantially the same outcomes as conjugal insemination programs.

## Egg donation

Egg donation is usually resorted to in the case of women who lack ovaries, suffer from ovarian failure, have experienced early menopause or are too old to procreate naturally. Fertilization of a spouse's sperm and a donated egg must take place *in vitro*. Egg donation requires a greater time commitment from the donor than sperm donation. Actually, the egg donor adheres to part of the IVF protocol, namely by taking medication to regulate and stimulate the production of ova before their removal.

### Recipient profiles

In general, women who use donated eggs do so because of their age (egg production decreases with age), because they experience early menopause or because they have suffered several *in vitro* fertilization setbacks with the use of their own eggs.

### Donor profiles

The vast majority of egg donors are recruited by applicants. Egg donors must be between 18 and 35 years of age, exhibit no exclusion criteria as defined by fertility clinics, be healthy and have a primarily altruistic motivation. A psychologist or nurse meeting a potential egg donor seeks to understand the woman's underlying motivations, her understanding of risk and her feelings about the fact that she will never be the social mother of the unborn child.

## Embryo donation

In Canada, embryo donation is a very rare practice. Only one clinic seems to have an embryo donation program. In Quebec, embryo donation does not yet exist, but at least one clinic plans to create such a program.

People are generally reluctant to donate their embryos once they are engaged in the full process of procreation. They prefer to keep a bank of frozen embryos, destroying them or offering them for research purposes once the project of having a child has been completed. Also, many couples find it difficult to decide the fate of spare embryos.

### The values at stake

For the Commission, gamete and embryo donation challenges the key values of the welfare of the child, the dignity of the human person, equality, reproductive autonomy and privacy.

The well-being of children is the responsibility of all stakeholders and implies that the child resulting from AP faces the same opportunities in terms of physical and psychological development as naturally conceived children.

The value of human dignity is contained in the principle that the human person itself should be considered as an end and not as a means to an end. This value excludes all forms of instrumentalization, reification and commercialization of the human body, its tissues, organs and products.

In terms of equality, the Commission has noted the disparities caused by Quebec legislation between gay and lesbian couples, men and women and between women. On the one hand, female lesbian couples can resort to artificial insemination with donated sperm, whereas co-parenting, which would allow a gay couple to have a child with a pair of homosexual women, is prohibited under Quebec law. On the other hand, a single woman can undertake a parental project through recourse to donated sperm, whereas the male equivalent is not possible because a single man would need recourse to a surrogate mother, something which is prohibited under Quebec law. Furthermore, by allowing a homosexual woman to become a mother without giving birth, the law creates a disparity between lesbian women and heterosexual women. In fact, when heterosexual women cannot bear children, they cannot aspire to become mothers, since a mother is the female person giving birth to the child. In addition to these disparities, the Civil Code draws a distinction between adopted children and children resulting from the donation of gametes: adopted children are able to access information about their biological parents starting at the age of 14 years, whereas children resulting from the donation of gametes are not allowed to access such information.

Reproductive autonomy may be defined as the ability of a person or couple to decide independently whether to reproduce or not and to choose the means to do so. Paradoxically, reproductive autonomy may imply that a couple or person will need a third person or a medical technology to achieve its parental project. While Quebec society recognizes the values of freedom of choice and autonomy, these values must also be reconciled with other values such as human dignity, welfare and the health of women and children.

Respect for privacy can be defined as the right to control information concerning us and to protect this information. As a result, this concept implies the freedom for individuals to keep certain information about them confidential. However, a component of the right to privacy – respect for one's identity – includes the right of the child to have access to its origins.

### **Ethical issues**

The third-party contribution to the parental project, through gamete or embryo donation, raises issues of two kinds. The first concerns the development of the child resulting from such a donation. This issue concerns the influence of the genetic bond in relation to the social bond, as well as the child's access to its origins, in conjunction with respect for the privacy of its parents and the right of donors to remain anonymous. The second issue concerns the concept of the dignity of the human person, the commercialization of the human body and its products, and the instrumentalization of human beings.

### **The development of children resulting from a donation**

Few studies on the fate of children resulting from a donation are able to shed light on their relationship with their parents and with donors possibly involved in the parental project. Indeed, the first studies on children resulting from AP were conducted primarily from an epidemiological perspective. While somatic data are beginning to emerge, very few analyses focus on psychological relationships and on parent-children interactions.

*Filiation: what importance should be accorded to genetics?*

The social bond between parents and children is a major component of the set of problems related to AP. Practices such as adoption or the restructuring of families after separation and divorce have changed the structure of the traditional nuclear family and have made social filiation more important.

However, couples or single people who wish to have a child “of their own”, are ready to resort to increasingly sophisticated methods or involve a third person in their parental project without this latter contribution being acknowledged. The desire to have a child biologically related to them may motivate some people to seek every means to achieve their end.

Why do people seek genetic filiation? Why is this filiation becoming increasingly important as reproductive technologies are developed? According to one hypothesis, the development of technology leads people to attribute greater value to the genetic bond in relation to the social bond. In this view, the use of available AP techniques thereby ensures that those unable to fulfill their desire for children are now able to exhaust every opportunity to have a child “of their own.”

Also, as mentioned in Articles 41 and 42 of the *Act respecting clinical and research activities relating to assisted procreation*, the Commission believes that scientific studies should be undertaken on the physical and psychological development of children resulting from AP and on the physical and psychological health of women participating in IVF protocols.

*The Commission therefore recommends:*

#### **Recommendation No. 1**

- That the Minister of Health and Social Services give the Institut national de santé publique (INSPQ) the mandate to establish a centralized mechanism for collecting non-nominal data in order to monitor the development of children resulting from assisted procreation, as well as the health of persons involved in assisted procreation;
- That this database be accessible to public health officials in fulfilment of the monitoring program, and to researchers whose research projects have been duly approved by the competent authorities, including a research ethics committee.

*Access to origins: should anonymity be lifted or not?*

In Quebec, gamete donation is normally anonymous. Gamete donors have neither rights nor obligations towards children whose conception results from donated gametes. On the other hand, certain mechanisms make it possible to reconcile the anonymity of a donor with the child's need to obtain information about the donor. This applies particularly in the case of medical information, knowledge of which may be necessary to protect life and health of the child.

However, anonymity gives priority to respect for the privacy of donors and to secrecy surrounding the circumstances of the child's birth. In so doing, by extension, it also deprives the child of the option of gaining access to its origins. According to many observers, the risk of disclosure in inappropriate circumstances of secrets surrounding the birth of children resulting from donations, and the legal impossibility for these children to gain access to information concerning them, come into conflict with the construction of identity, the well-being of children and the sense of belonging to a family.

The Commission recognizes that in some cases, because of the family and cultural context in which the child is developing, disclosure is not always in its interest. It considers nonetheless that fertility clinics should routinely offer their customers a form of counselling to help them make an informed decision about the appropriateness of informing the child about the circumstances surrounding its birth. In this regard, counsellors should clearly highlight the potential effects of secrecy on the child and on the whole family.

The Commission believes in the importance, on the one hand, of ensuring that a balance is achieved between the interests involved and, on the other, of giving precedence to the well-being of the child, while avoiding the creation of disparities between adopted children and those resulting from AP. It believes that it would be wise to proceed one stage at a time.

*Whereas it is better to let gamete donors be the first to lift the anonymity of their donation, instead of proposing a total lifting of anonymity, the Commission recommends:*

**Recommendation No. 2**

- That the Quebec government amend the Civil Code of Quebec to address the disparity in rights between adopted children and children resulting from donations, with respect to access to their origins, by applying the same practice as in matters of adoption;
- That appropriate counselling be offered routinely, not in a context of self-regulation, but as part of a regulatory framework instead. Such counselling should address both gamete donors and people resorting to donated gametes or embryos, in order to make them aware of the importance for the child of knowing its origins and the implications of lifting anonymity.

**Respect for the dignity of each human being**

Human dignity is a vague and hard-to-define concept, but is nonetheless a concept at the heart of values professed by democratic societies, including Quebec society. In this regard, and from an ethical perspective, the donation of gametes raises the issue of the instrumentalization of the person.

### *The non-commercialization of the human body and its products*

The Commission rejects outright any idea of challenging the principle enshrined in law of the non-commercialization of human body. However, altruism does not seem to be enough of a motivation to attract a sufficient number of gamete donors to meet the needs of infertile people. Different measures involving some form of monetary exchange have been developed in the context of gamete donation. In order to pursue further analysis in this position statement, the Commission identifies three monetary measures, namely compensation, the payment of an indemnity and the reimbursement of expenses.

The Commission has found that this apparently straight-forward question does not easily yield an answer. Indeed, it may at first seem obvious that the non-commercialization of the human body and its products should take precedence over all other considerations. However, the value of equity affects various facets of the set of problems involved in assisted procreation, and to varying degrees – and this in turn is transforming reflection itself into a true dilemma. The Commission also shares the concern of couples or individuals who wish to obtain a gamete donation and who are somehow penalized by the lack of gametes available to meet their needs. Accordingly, while compensation is already prohibited, should an indemnity package also be prohibited, at the risk of creating inequality between egg donors and sperm donors? Should such an indemnity be allowed instead, at the risk of creating an inequality between better-off donors and those less-well-off? Is it acceptable to prohibit a practice likely to increase the number of gamete donors, which could possibly compensate for the scarcity of gametes?

Nevertheless, the Commission believes that not everything should be reimbursed or indemnified, and that donation is a personal choice requiring a good dose of altruism. Given that human products are involved, the scarcity of these products should not be invoked as a reason for the use of monetary incentives. A risk-benefit analysis shows that the scarcity of gametes alone (and the benefits of a greater availability of gametes where donations are subject to higher compensation or indemnity) do not constitute a sufficient reason, considering the risks that could arise from compensation or overcompensation of gamete donation (the risks of exploitation, discrimination, commercialization of the human body, health risks for women, etc.). The reimbursement of expenses upon presentation of receipts would attract people who are really interested in the idea of helping infertile people. Moreover, such a practice would prevent donors from disbursing funds in order to make their donation, while acknowledging the action they have taken.

It could be possible to envisage setting up a bank managed by a central agency, like Héma-Quebec, for example, mandated to take over the management of donated gametes produced in Quebec and, in the event of a shortfall, to obtain sperm from outside of Quebec.

*Whereas donation is based on altruism and the non-commercialization of human body is an inviolable principle, the Commission recommends:*

### **Recommendation No. 3**

That the Minister of Health and Social Services establish an agency to regulate approved clinical practices for the storage of gametes and embryos, for recruitment, reimbursement of expenses and the traceability of gamete donors, and for raising awareness of these risks and responsibilities associated with their actions.

#### **The non-instrumentalization of individuals**

Is there a societal obligation to satisfy the desire of infertile people for a child, at all costs? This is the main issue the Commission has raised with respect to the selection of gamete donors by clinics and parents. The Commission also wonders how such a selection could lead to the instrumentalization of persons.

In ethical terms, the attempt to determine a maximum number of characteristics for the unborn child could hamper this child's symbolic freedom, namely to be born for itself as a unique individual with its own project. Indeed, from that time on, the question at issue is no longer that of having a healthy child, but of having a child with specific characteristics that meet the expectations of prospective parents. In the United States, prospective parents may consult "catalogues" of sperm donors, choosing a donor based on a pedigree that suits them (education, physical, artistic or athletic skills, etc.). This practice suggests that the child is a consumer product, an object to be customized according to the wishes of parents.

For the Commission, such a practice is unacceptable and constitutes the instrumentalization of the unborn child.

*Whereas Quebec society should avoid developing practices such as creating "custom-made baby" through the selection of gamete donors, and whereas, under current conditions, the confidentiality of origins is protected and the minimum matching of physical characteristics with the father poses no risk to the child and may even encourage its integration into the family and society, the Commission recommends:*

### **Recommendation No. 4**

That the only permissible criteria for donor selection, in addition to medical criteria, be physical criteria for matching with one intentional parent, where this seems to be justified by the welfare of the child.

#### **The supply of gametes for infertile individuals**

Although the Commission gives priority to the interest of the child and the dignity of the human body and its products, it has decided to consider five options for mitigating the effect of any (partial or complete) lifting of anonymity and the impact of freely donated gametes on the offer made to infertile persons: directed donation, paired donation, shared donation, posthumous donation and embryo donation.

### *Directed gamete donation*

In the case of directed donation, the couple or single woman recruits a donor (a sister, friend, colleague, etc.) who provide her own eggs. This type of donation is not anonymous. This gives rise in turn to a number of ethical concerns: do the donors risk being pressured by those around them to donate? What assurance is there that no exchange of money between people is involved? In addition, recipient couples or women may fear that the donor could interfere during pregnancy or become too attached to the child, or that she could one day tell the child all about its status. Conversely, there are cases where donation has strengthened the bond between the donor and the recipient or recipients. The Commission considers that the directed donation of gametes is acceptable as long as donors and recipients receive appropriate counselling so that they may make an informed decision.

Using donations from within the family raises many ethical issues, including the impact of this practice on the sociological and anthropological foundations of parenthood, and even on the identity of individuals. Two scenarios are possible: intragenerational and intergenerational donation.

An intragenerational donation refers to gamete donation between collateral relatives, that is, between two siblings or within the extended family. The Commission believes that intragenerational donations require appropriate counselling to ensure that no family pressure is exerted on potential donors and that each party to the donation understands the emotional risks associated with such donations, including risks arising from the rearrangement of the filial bonds.

Intergenerational donation, for its part, is far from being universally accepted. Since it involves the donation of gametes or embryos from one generation of a family to another generation, the incestuous character of the donation constitutes a significant source of discomfort. Moreover, most authors dealing with the donation of gametes from a sociological or anthropological point of view use the argument of incest in opposing this type of donation.

Family pressure is also a major component of this problematic situation. There may be pressure on the mother to donate her eggs to her daughter (out of guilt or from a sense of duty) and once the opportunity to do so arises, it may seem impossible to backtrack.

Moreover, intergenerational directed donations could have serious emotional consequences for children because of the resulting confusion in family relationships. In addition, given that the mother may somehow be the grandmother, aunt or sister of the child conceived in this way, temporal and generational boundaries are being transgressed. Theoretically, by means of directed embryo donation, a woman could bear her own brother (for example a couple having kept frozen embryos following fertility treatments could provide its own daughter with surplus embryos). The opposite could also happen, for example in the case where older women used the eggs of their daughter.

*Whereas the directed intragenerational donation of gametes may be acceptable if properly monitored, whereas intergenerational directed donation endangers the welfare of unborn children, the Commission recommends:*

#### **Recommendation No. 5**

- That the intragenerational donation of gametes be practiced in an environment that eliminates any possibility of consanguinity;
- That those involved in intragenerational gamete donation receive appropriate counselling so that they may properly assess the potential impact on filial bonds and their relationship with the donor as well as the future relationship between the donor and the child;
- That intergenerational donation be prohibited since it transgresses temporal and generational boundaries.

#### *Paired donation*

Paired donation resembles directed donation except that the donor does not provide her eggs to the specific couple or person recruiting her. Instead, she will be matched with another couple or single person who has recruited a donor. The Commission considers that paired donation is acceptable, provided that parties receive appropriate counselling.

#### *Shared Donation*

The shared donation program aims to convince women and couples who cannot afford to pay for their treatment to donate some of their eggs in exchange for a reduction in the cost of treatment. The question then arises: can cost-sharing be construed as a form of pressure, not to mention commercialization?

Shared donation is not contrary to the interests of the child, but is of little interest given that first cycles of IVF are reimbursed by the State in Quebec. However, the main interest of this type of donation is the financial incentive, which runs counter to the principle of non-commercialization of the body, unless egg sharing has an altruistic motivation. In the latter case, it is acceptable, provided that parties receive appropriate counselling.

#### *Donation and posthumous insemination*

The Commission has studied the following scenarios: gametes from a donor who is now deceased, gametes collected from a man or woman after death, gametes already collected in fulfilment of a parental project before the death of the spouse, embryos created in fulfilment of a parental project before the death of the spouse. The Commission has devoted particular attention to two of these cases because of the ethical issues they raise.

**Gametes collected from a man or woman after death.** The Commission believes that in this context, precedence should be given to compliance with the previously expressed wishes of the donor. In this regard, it recalls and endorses the principle stated in Article 8(2) of the *Canadian Assisted Human Reproduction Act*, namely that it “No person shall remove human reproductive material from a donor’s body after the donor’s death for the purpose of creating an embryo unless the donor of the material has given written consent, in accordance with the regulations, to its removal for that purpose.”

*Whereas it is possible that this provision may be declared unconstitutional by the Supreme Court on the grounds that it encroaches on the powers of the provinces, the Commission recommends:*

### **Recommendation No. 6**

That the removal of gametes from a deceased person be prohibited if the deceased person has not previously consented to it.

**Embryos created in fulfilment of a parental project before the death of the spouse.** The Commission believes that the surviving spouse go through a minimum period of reflection before the embryo is transferred. In addition, due attention should be paid to pressures possibly exerted by in-laws.

There are very few studies on the subject. However, there is little difference between the situation of children developing in a single-parent context and children resulting from the insemination of single women.

*Whereas the widow needs to go through a period of reflection, while respect needs to be upheld for the reproductive autonomy of individuals as part of a parental project, the Commission recommends:*

### **Recommendation No. 7**

That insemination or embryo transfer be permitted only on condition that all the following criteria are met:

- The removal of gametes or fertilization has occurred before death;
- There is written consent of the deceased indicating his or her agreement as provided in their parental project;
- The widow was able to go through a period of reflection and receive adequate counselling in order to make an informed decision.

### *Embryo donation*

Embryos for donation are spare embryos that are no longer need to implement a parental project. Embryo donation is a rare practice in Canada, and does not yet exist in Quebec. Many couples find it emotionally difficult to decide the fate of surplus embryos. Furthermore, a significant proportion of frozen embryos are stored in the banks of fertility clinics, where they await destruction or use for reproductive purposes or for research.

It is important that donors and recipients receive professional and independent counselling about the disposal of spare embryos. This counselling should be available to potential donors in the early steps of assisted procreation so they can prepare for the possibility, on the one hand, of donating their embryos and, on the other hand, of being in a position to provide informed consent without undue influence from anyone.

*Whereas the stakeholders involved need to be adequately informed, the techniques for freezing embryos are improving, and embryo donation means that recipients avoid the risks and disadvantages associated with IVF, the Commission recommends:*

#### **Recommendation No. 8**

- That people who use assisted procreation receive all information necessary to make an informed decision about embryo donation at an early stage of the process, but also later, when the assisted procreation process has been completed or abandoned and when there remain spare embryos;
- That programs based on anonymous donations of surplus embryos be favoured. To this effect, that people be encouraged after the initial success of assisted procreation to provide their written consent to donate their surplus embryos. After a period of three years, unless the owners of these embryos have made a specific request use these embryos, extend their conservation or destroy them, the embryos should be donated anonymously.

#### **Prevention and education: acting before the initial stages of assisted procreation**

Among people resorting to assisted reproductive technologies, many do so because of infertility or subfertility. Whereas these techniques are rarely the first choice for couples, it is crucial to focus more research on the causes of infertility, including the postponement of pregnancy. By taking steps pro-actively, through prevention and education, the Commission considers that demand for AP will likely decrease, thereby reducing the number of people exposed to risks associated with these techniques. More preventive measures should be taken to address male and female infertility.

*Whereas prevention may take the form of public policies aiming to raising awareness among the population of the causes of infertility and the risks of childbearing at a later age, the Commission recommends:*

#### **Recommendation No. 9**

- That the Minister of Health and Social Services fund a public awareness campaign on the known causes of infertility and the ways to preserve fertility;
- That the Quebec government reinforce socio-economic measures and public policies that incite people to engage in parental projects at an earlier age;
- That the Quebec government fund research programs on the prevention of infertility.

## SURROGACY: MAINTAINING THE LEGAL *STATUS QUO*

Surrogacy generally includes all situations where a woman goes ahead with a pregnancy, not because she intends to keep the child and take on the social role of mother, but in order to hand the child over, at birth, to a person or a couple with whom she has contracted for this purpose.

New kinds of surrogacy are emerging nowadays. The most common kind is where the surrogate mother is inseminated with sperm from the spouse of a woman who can neither conceive nor carry a child. In this case, the egg used is provided by the surrogate mother. In fulfilling the roles both of direct parent and of surrogate mother, this woman may thus be considered a “substitute mother”. A homosexual couple may also consider recourse to a surrogate mother. The semen of one of the homosexual partners is then used for intra-uterine insemination of the surrogate mother.

With the development of assisted procreation, a new form of surrogacy has emerged: one in which the eggs of the surrogate mother are not used for fertilization and where the surrogate mother carries and gives birth to the child. In this situation, an embryo already conceived *in vitro* is transferred into the uterus of a woman who will carry and give birth to it, on behalf of the couple or person whose gametes were used or, in some cases, who have resorted to donors.

It is important to understand that in such cases, the woman has no genetic bond with the child she carries for a third person. This is also why IVF tends to be used rather than insemination of a surrogate mother with the spouse’s sperm, in order to prevent the surrogate mother from becoming too attached to the child.

In Quebec, there is very little documentation about surrogacy since the contracts providing for it are not binding and have no legal value: in the eyes of the law, these contracts are absolutely null and therefore unenforceable.

### The legal framework

In Quebec, surrogacy contracts are not recognized in law. They are considered unlawful, because they are contrary to public order.

However, while surrogacy contracts are considered unlawful and therefore unenforceable in civil law, they may not strictly speaking be illegal, in other words, punishable by fines or imprisonment. Indeed, the Canadian *Assisted Human Reproduction Act* criminalizes certain practices but does not prohibit surrogacy as such; the act only prohibits payment for surrogate motherhood, payment of intermediaries, or the placing of advertisements to obtain the paid services of a surrogate mother. On the other hand, the law prohibits members of the medical profession from assisting a female person to become a surrogate mother, knowing or having reason to believe she is under 18 years of age. Although the act

presents the practice *a contrario*, the practice is nonetheless subject to control and, in some way, is legitimized by federal law. Consequently, *a priori*, a dichotomy exists between criminal and civil law, which has had the effect of causing some confusion between what is void and what is illegal, for clinicians practicing in this area.

### The context of practice

For the time being, the practice of surrogacy is somewhat limited in Quebec. It is however possible that Quebec couples may have resorted to surrogates abroad, just as Quebec women may have been recruited by people living abroad to carry their child. Given the lack of data in this regard, it is not possible to assess how high the demand for surrogates is, or to determine what agreements are being concluded and what the real motivations of surrogate mothers are. Yet, as difficult as it is to measure the scope of surrogacy, the practice exists in Quebec as elsewhere, and it raises a number of ethical issues.

### Ethical issues

The issues at stake are much the same as those the Commission has identified for gamete donation, with one exception. It may be difficult for the child to establish who its parents are, and this may become a source of conflict, even to the point where the child has no status, in other words the child is without either mother or father. For the child, surrogacy constitutes a major issue, quite apart from the difficulties the child may face in having two mother figures. In the Commission's view, the well-being of the child is the primary value to be considered and goes to the heart of the issues raised by surrogacy. However, the practice of surrogacy also affects other values, including women's health and autonomy, and the dignity of the human person, which involves the principle of the non-commercialization of human body, a principle opposed to any form of instrumentalization of the person.

### The status of the child

In Quebec law, motherhood is determined by the birth of a child, which is duly recorded in an attestation of birth; motherhood cannot be challenged on the grounds that the egg or embryo is not from the woman who carried the pregnancy to term. It is from this attestation of birth and the subsequent declaration of birth, signed by the parents, that the birth certificate is established, providing normal proof of filiation.

Based on these premises, three scenarios are possible: the surrogate mother decides to keep the child; she hands it over to the prospective parents – and in so doing, she fulfils her obligation to them; or, finally, none of the actors involved wants to keep the child and it is left without status. In each case, the child's filiation is problematic, and it may be necessary to settle the matter in court.

### The development of the child

Contrary to egg donation, surrogacy can create another type of cleavage in motherhood: the social mother may be the genetic mother, although she is not the one carrying the child.

Surrogacy therefore highlights a dichotomy, a distinction between the surrogate mother and the fetus itself. Surrogacy underlines the idea that the fetus is a being "apart" from the woman carrying it, and this in turn potentially has consequences for the well-being of the surrogate mother and the child she carries.

According to some observers, the child's healthy development would seem to depend on the environment provided by the parents and the love they lavish on the child. For others, the permanent abandonment of the child at birth by the woman who brought it into the world is somehow irreparable. This theory of the importance of the early relationship established between mother and child during pregnancy does not meet with universal acceptance, however.

It is important to note once again that while the studies published so far are reassuring, there are still few longitudinal studies devoted to the long-term effects on children resulting from surrogacy arrangements.

According to some psychiatrists, children having to cope with several maternal figures may have difficulty in resolving potential conflicts arising from this situation and may find it difficult to fulfill themselves. Particularly during adolescence, a child resulting from surrogacy may feel a contradictory sense of dual loyalty, on the one hand towards the woman who bore it and on the other towards the intentional parents who wanted it and who consider it as their own.

#### Access to origins

Motherhood can be distributed between two or three women and paternity attributed to one or two men, involving a total of three to five distinct persons in the conception of a child.

In this context, should secrecy be maintained or should the focus be placed on truth about the child's origins? A way should be found to decide whether it is better for the child to be aware of its origins or whether the secret should be kept, while bearing in mind all the implications that such secrecy can have on the child's life.

However, the issue of the secrecy of origins and of anonymity takes on particular dimensions in cases of surrogacy, since it is based on an agreement between parties. A surrogate mother may end up intervening in family life.

#### Women's health

Among the risks to the physical health of the surrogate mother may be noted the possibility of miscarriage, ectopic or multiple pregnancy and medical complications that increase with the age of the mother and the complexity of her reproductive history. A woman is not required to have a child and she can decide not to, but may she legitimately transfer that risk to another woman, especially if she is resorting to surrogacy for non-medical reasons?

The surrogate mother may also be subject to risks to her psychological health. For example, in "handing over the child" she carried to the couple who desired it, she may experience suffering and mourning.

#### Women's autonomy

Surrogacy underlines the idea that the fetus is a being "apart" from the woman carrying it, and this in turn potentially has consequences for the autonomy of the pregnant woman. The Commission is concerned that women who act as surrogate mothers no longer have the autonomy normally accorded to a mother carrying her child. Indeed, prospective parents do not necessarily focus on the well-being of the surrogate mother, but rather on the well-being of the unborn child. And even if prospective parents do show concern about the woman's well-being, how can one be sure that it is as a "surrogate mother" rather than as a person? Moreover, prospective parents may

exert pressures on various aspects of the situation, such as the surrogate's lifestyle, monitoring of pregnancy and childbirth. She must also submit to procedures and examinations offered by the medical team and adopt behaviour conducive to development of a healthy child.

This distinction between the pregnant woman and her fetus is problematic for the whole community, because it calls into question the foundations underlying the right to abortion, and to the integrity, security and autonomy of women. In the Commission's view, reproductive autonomy is established and cannot be questioned, and it is up to the surrogate mother, and to her alone, to take decisions regarding the development of pregnancy, particularly if she eventually signalled her desire to seek an abortion.

Finally, in the event that the surrogate is a friend or sister of an adoptive parent, additional risks of pressure may arise, leading to delicate situations and psychological difficulties for the people concerned. Relationships existing before pregnancy can have positive or negative impacts on the contractual relationship. In addition, unlike the case of a "foreign" surrogate mother with whom parents may decide *a priori* to break off all contact following the child's birth, a surrogate mother who becomes an aunt, or who remains within the close circle of friends of the "adoptive" couple cannot be easily pushed aside after birth. An additional psychological challenge therefore resides in the way relations are managed between the adoptive couple and the surrogate mother, on the one hand, and between the child and the surrogate mother, on the other hand.

#### The non-commercialization of the body and the non-instrumentalization of persons

Surrogate mothers may find satisfaction in helping a couple have a child: the surrogate mother does not derive a direct benefit, beyond the feeling of having helped a couple fulfill their project of having a child. Other women may become surrogates simply for the pleasure of being pregnant. Still others become surrogates in order to make money, while some see it as a way to escape poverty and even to bring some dreams and life projects to fruition. Surrogacy entails the potential exploitation of women, especially of poor women.

In this context, the reimbursement of expenses upon presentation of receipts would have the effect of avoiding the prospect of financial gains, while sparing surrogate mothers the need to bear other pregnancy-related costs on their own. However, making a lump sum payment could discriminate between women, since it could make it seem more advantageous to carry a child on behalf of others than for oneself. Hence the importance for women contemplating surrogacy to be well-informed about the risks they face; to understand that all pregnant women face these risks; while the risks themselves should not easily be assigned monetary values.

In addition to the risk of exploitation of the woman and her body, surrogate motherhood poses a risk to the child who somehow becomes a commodity that can be bought or sold.

#### Cross-border reproduction

Canadians and Quebeckers go abroad every year to procure assisted procreative services that are not available here, or are too expensive. Conversely, and for similar reasons in their country of origin, people living abroad come to Canada. For their part, donors also move from one place to the next, in order to get a better price for their gametes.

Cross-border reproduction (commonly called “procreative tourism”) is disturbing for several reasons: it is only an option for people who can afford it; all control of quality or of security of services offered is impossible – which may pose risks for mothers and children; and it involves and increases the risk that women living in developing countries will be exploited by more affluent foreigners. In addition, since legal prohibitions are generally a reflection of social consensus, it is disturbing that some people circumvent the laws of one country to go to another, where laws are more lax. Procreative tourism also underlies the notion that human reproduction is an object of commerce. The terms “baby business” and “reproductive industry” also illustrate this integration of human reproduction into the domain of commerce.

A question also arises about the responsibility of physicians with respect to procreative tourism. When physicians know that their patients may be tempted to resort to a more open country, should they close their eyes or should they guide their patients towards more acceptable solutions instead? Are they in effect complicit, when making a technical intervention, for example conducting an ultrasound for a woman they know has bought eggs abroad? Can the medical act be dissociated from the whole process of assisted procreation? While doctors have a duty to care for their patients, they should not encourage procreative tourism.

The argument of procreative tourism is invoked each time AP is regulated. The Commission believes that in addition to going against the values of society, easing the laws would do nothing to solve the problem. In Commission’s view, yielding to this temptation is not an acceptable option.

*Whereas surrogacy entails risks of exploitation of women that are ethically unacceptable and considering that such a practice would lead to a form of reification of the child that the Commission cannot endorse.*

*Whereas the prohibition of surrogacy may encourage procreative tourism and thus increase the risk of exploitation of poor women abroad, the Commission contends, however, that this is not a sufficient reason to violate the value of human dignity upheld by Quebec society.*

*Further considering the risks to the autonomy, health and integrity of women, the physical and psychological risks for all actors involved, and considering that surrogacy is a form of instrumentalization and commercialization of the female body and of the human being, the Commission recommends:*

#### **Recommendation No. 10**

That the Government of Quebec maintain the principle of the nullity of surrogacy contracts.

## PREIMPLANTATION GENETIC DIAGNOSIS: MONITORING PRACTICE IN ORDER TO AVOID DRIFT

For many years now, the development of obstetric knowledge and access to certain technologies have been helping people who need medical support to maximize their chances of having healthy children. For example, screening tests for certain diseases are carried out as part of the monitoring of pregnancy; maternal blood tests and ultrasound tests are also undertaken. Additional, more specific tests may be undertaken, such as determining the genetic profile of the fetus. All of these techniques make up what is called prenatal diagnosis (PND).

More recently, a diagnostic method has been developed at a much earlier stage: preimplantation genetic diagnosis (PGD), whose initial objective is to offer an alternative to prenatal diagnosis. Specifically, PGD involves the genetic analysis of cells taken from an embryo derived from *in vitro* fertilization before its implantation in the uterus.

PGD is used in cases of *in vitro* fertilization, and occurs at the early stage of development of the embryo before implantation in the uterus. As such, PGD avoids recourse to abortion, whether spontaneous or medical, which may result from PND. However, for people with no fertility problems who would like to access PGD, it inevitably requires invasive and costly infertility treatments.

Both of these diagnostic techniques – PND and PGD – have a potential for much wider uses than other techniques currently available. PGD first appeared in the 1980s, but preimplantation genetic diagnoses were undertaken on a broader scale in the 1990s. Even though PGD is available everywhere in the world, its practice is still fairly limited.

### The technique: two main objectives

At the present time, PGD is used to undertake two major types of genetic analysis, in order to ensure better outcomes for IVF:

- the karyotype, that is to say, the study of chromosomes, which can detect abnormalities in the number of chromosomes (as in the case of trisomy 21) or in their morphology, and also to identify the sex of the embryo (XX or XY); maternal age (35 and older) is the most common reason invoked for undertaking this analysis;
- diagnosis of DNA molecules by amplification, which is undertaken to identify monogenic inherited diseases, whether they be autosomal recessive disorders (for example cystic fibrosis or mucoviscidosis and spinal muscular atrophy), autosomal dominant disorders (such as Steinert's disease or myotonic dystrophy and Huntington's disease) or recessive X-linked disorders (such as Duchenne muscular dystrophy and X-linked myotubular myopathy), transmitted by women, and affecting only men.

In the context of assisted procreation, it used to be customary to undertake PGD in order to check embryo implantability in the mother. However, this practice is tending to disappear, because PGD may damage or even destroy the embryo; the benefits sought (improving the chances of implantation) are no longer considered to outweigh the risks. Screening is still used to assess embryo implantability, but the technique now used is much less risky for embryos.

Although PGD services are available across Canada, only two laboratories in the country are able to undertake preimplantation genetic diagnosis itself. Biopsies are usually shipped to the United States for analysis.

## The regulatory framework

In Quebec, under the new law on assisted procreation, PGD can only be performed in a centre for which a licence has been issued by the Minister of Health and Social Services, as is the case for all assisted procreation activities. The conditions and standards for these activities are not yet known; they will be established by regulations in the near future, and it is reasonable to expect that the centres authorized to practice PGD will have to implement standard operating procedures. For its part, the Canadian law on assisted reproduction does not expressly mention PGD, but it prohibits certain uses, including sex selection for non-medical reasons.

Currently, PGD is for all practical purposes banned in countries such as Germany, Austria, Italy and Switzerland, even if no law explicitly mentions it. In most countries of the European Union that have chosen to regulate PGD, its practice is in general limited to the detection of chromosomal abnormalities and to cases where there is a risk of hereditary transmission of a severe early-onset genetic disease which is recognized as incurable at diagnosis. In the United Kingdom, the use of PGD for purposes of “family balancing” is expressly prohibited by law. Other prohibited practices include selecting embryos carrying a disease or abnormality in preference to those lacking such a disease or abnormality (i.e. the voluntary promotion of the birth of disabled children).

The application of PGD for medical reasons benefitting a third person (HLA or immunogenetic typing), an application most commonly referred to the practice known as “designer baby”, was recently legalized in Belgium, Denmark, France, Spain, Norway, Sweden and the United Kingdom. On the other hand, it is strictly prohibited in the Netherlands.

A greater number of European countries have legislated on PGD, but countries on several other continents have also legislated in this area. The practice is subject to regulations for example in New Zealand and also in several States of the federation of Australia, such as the State of Victoria. At the present time, the guidelines of the American Society for Reproductive Medicine govern the practice of PGD in the United States. This association endorses neither sex selection for reasons of convenience nor genetic testing for the purpose of increasing the success rate of IVF, given the results obtained.

The PGD regulatory framework is thus derived from many sources. In North America, it involves more self-regulation, whereas in Europe there is a greater tendency to establish a legislative or regulatory environment. While there are many different positions regarding the legitimacy of PGD, there is nevertheless consensus about limiting the practice to medical indications. These indications are however subject to different interpretations in each country, which leads to the conclusion that there is a plurality of positions on PGD.

## General reflections on the use of PGD

Preimplantation genetic diagnosis is now offering applications that generate debate. For some people, any use of PGD can be ethically justified in terms of the reproductive autonomy of individuals and protection of the child's or the community's welfare, especially when genetic diagnosis aims to avoid suffering and the costs of certain genetic diseases or abnormalities. For others, PGD and the selection of genetic traits are unacceptable, whatever the reason invoked, since genetic selection is related to the quest of the perfect baby and to a liberal form of eugenics. Both these positions are extreme, however, and most views are situated in an intermediate zone where the acceptability of PGD use is determined based on the context and the nature of the reasons motivating such use.

### The change in the meaning of assisted procreation

Originally, PGD was developed because it could help avoid the use of PND and forestall the decision to abort which could result from PND. Nowadays, preimplantation genetic diagnosis is being offered on an ever-broader scale, not only to people who need medical assistance to conceive, but also to single people or couples, whether fertile or infertile, who want the benefit of such a diagnosis for embryo selection (whether because they know they are at risk of transmitting a genetic disease, or because they have a seriously ill child, etc.).

This broadening of the reasons justifying access to assisted procreation is somehow changing the meaning of AP, which is now becoming seen as a way to select an embryo that will become a healthy child or, where appropriate, a child with genetic characteristics sought by its future parents (such as immunogenetic compatibility or gender preference).

The development of PGD raises the burning question of how far it is acceptable to go to meet the desire for a *healthy* biological child or one with specific genetic characteristics.

### The complexity and risks of the procedure

An analysis of issues related to PGD must take into account the complexity and the risk associated not only with PGD itself, but also with the related procedure of IVF. PGD is often presented in certain contexts as an alternative to PND, yet it is not a harmless solution. Resorting to PGD involves physical and psychological constraints that pose risks to all those involved.

For the embryo, the removal of cells as part of the diagnostic technique involves some risk for gestational development as well as development of the child at a later date. For women, the main constraints are related to IVF procedures and their share of risks and inconveniences, whether physiological or psychological.

The medical team may experience significant psychological and clinical problems, when they are witnesses to the tensions felt by the couple or single person, and those around the decision-making process. In the absence of clear guidelines concerning indications and acceptable practices, some professional teams experience discomfort when faced with unusual requests.

Another point worth noting in this respect is that the likeliest outcome of PGD is multiple pregnancy and multiple births, since more than one embryo is implanted to increase the chances the procedure will be successful. Given all the risks and disadvantages PGD poses for the embryo, and the various constraints it imposes on the woman, the couple and the medical team, it is hard to consider it as a accessible solution whose consequences are easy to live with.

#### Innovative character and risk assessment

While the constraints induced by PGD can be identified, it must however be noted that the direct (physical or psychological) consequences flowing from this procedure are hard to assess accurately. To date, not enough PGD procedures have been undertaken to allow a good grasp of all the ins and outs of PGD, a solid understanding of the risks involved and any certainty whether the procedure will work or not.

The Commission therefore considers that the innovative character of PGD should be clearly explained to those who opt for it, including the need to more fully document its risks and consequences, and the fate of surplus embryos that are usually subjected to cryopreservation.

The success of PGD is not guaranteed and medical errors may occur, particularly given the limited time available for analysis (12 to 24 hours). These errors can occur for various reasons, including an unfortunate choice of healthy cells or the opposite, for example, or the existence of an abnormality that is not part of the analysis, and therefore goes undetected. In addition, in the light of current research, it is not yet possible determine whether the samples taken from the embryo through PGD can affect the fetus or the child at a later date.

For all these reasons, many clinics recommend that their clients also seek prenatal diagnosis to confirm the outcome of PGD, despite the additional risks this poses for the fetus and for miscarriage. Parents should definitely be made to understand that PGD does not provide an absolute guarantee against the future development of disease.

The decision whether or not to resort to PGD should always strike a balance between the severity and frequency of risks, on the one hand, and the benefits of selecting embryos for preimplantation, on the other. Whatever the circumstances, it is important that sufficient and adequate counselling be provided to those persons involved so they can make a choice that is truly free and informed, especially if the health of the unborn child is a primary concern. Moreover, appropriate information should be provided on other options at their disposal, for carrying out (or, as the case may be, for not carrying out) their parental project.

*Whereas limited research has been undertaken on long-term monitoring of the health status of children resulting from assisted procreation who have also undergone PGD during the embryonic stage, as well as the innovative character of PGD, the Commission recommends:*

#### **Recommendation No. 11**

- That the Minister of Health and Social Services establish a specific licensing mechanism for approval of centres performing PGD;
- That the Fonds de recherche en santé du Québec (FRSQ) set up a research program for evaluating the risks of PGD for embryos and children resulting from this procedure.

#### **The values at issue in PGD**

The values that particularly concern the Commission de l'éthique de la science et de la technologie in its reflection on preimplantation genetic diagnosis are the health and well-being of children, the dignity of these children, the reproductive autonomy of individuals and the equality of all human beings.

#### **The health and well-being of children**

In ethical terms, what clearly distinguishes assisted procreation from other medical practices is its outcome: the “therapeutic” techniques involved in AP lead to the birth of a human being.

Although the welfare of the child is subject to different interpretations, this value can be understood in the context of AP as one involving rigorous medical responsibility for the safety of diagnostic techniques and for physical risks faced by children resulting from PGD. In addition, the Commission considers that this value is related to a responsibility borne by all actors involved in decision-making about PGD, to ensure that the child resulting from it has the same chances as children conceived naturally with respect to physical and psychological development.

In this sense, the Commission is concerned about the negative consequences of a birth attended by a serious disabling illness, for which no treatment is available and that will seriously jeopardize the quality of life of the child. However, promoting health and well-being does not amount to selecting the most genetically perfect or the highest-performance children. Indeed, a child selected *on account* of such genetic characteristics could become “responsible” for becoming what its parents hoped for, without the parents necessarily being aware of the fact. Promoting the welfare of the child therefore means taking into account the physical and psychological health of the child resulting from PGD. In the view of the Commission, this welfare also means that the child should be allowed to be born in a context that, emotionally, will be most conducive to its harmonious overall development.

## The dignity of the child

In terms of assisted procreation, the dignity of the child refers to two principles that underlie this value and that arise in certain clinical situations, most often in connection with requests from people who want a preimplantation genetic diagnosis. These two principles are the non-instrumentalization of human beings and respect for symbolic freedom.

With regard to the non-instrumentalization of human beings, the Commission endorses the principle that the human being should be an end in itself; it should never be considered solely as a means to an end. Concerning PGD, this means that embryo selection should not be viewed primarily as a means to meet special needs. This principle of non-instrumentalization is particularly threatened when PGD is undertaken in order to select an embryo that has a compatibility enabling it to be a donor, usually for an already specified purpose. In this situation, the child is born *because* it is compatible, and it is selected *in order* to be a donor.

The symbolic freedom of a being refers to the lack of predetermination in the direction the life project of each human being takes. In the case of PGD aimed at the health of the child, it is not clear that the symbolic freedom of the child is endangered, as such, although the argument of the slippery slope underscores the deterministic potential caused by advances in human genetics. In the case of diagnosis for the voluntary birth of a child with a disability, for example, it is clear that the child will have to assume a decision taken by its parents and the possibly serious consequences stemming from this decision. Furthermore, the risk of eugenic drifts or of limiting the symbolic freedom of beings resulting from PGD is cause for concern, especially given the development and improvement of diagnostic practice. As technology continues to evolve, it is conceivable that the identification of new genes would incite prospective parents to seek embryo selection, based on genetic discoveries and according to subjective preferences, which could be influenced, possibly in an insidious fashion, by a kind of social norm.

## Reproductive autonomy

The value of reproductive autonomy of individuals and couples is defined as the ability of a person or couple to decide whether to reproduce or not and whether to resort or not to various available means in fulfilment of a parental project. The development of diagnostic techniques and expanded indications of preimplantation genetic diagnosis raise questions, however, about whether the free choice of individuals is respected in all situations. Indeed, it seems that certain parental requests are challenged by values such as respect for the dignity of the child and protection of its welfare and respect for equality among people. These situations create real value conflicts.

In terms of reproductive autonomy, PGD challenges the scope of that value and poses an ethical issue: how far should we go in recognizing the private nature of the decision of couples or individuals to resort to embryo selection on the basis of genetic analysis? Should the severity of disease be defined only for couples? Is reproductive autonomy unlimited? If reproductive autonomy has limits, what are they and how can they be justified ethically?

In the context of reproductive health, private decisions reach a limit when they are likely to hinder the autonomy of a person very closely involved in the situation: the child. Given the opportunities and risks posed by PGD, promoting the reproductive autonomy of couples comes with a significant requirement: it requires that the procedure is resorted to, on the basis of on a free and informed decision.

Although people starting PGD are physically and mentally healthy and capable of making rational decisions, they are nonetheless subject to some form of vulnerability. Professionals monitoring such requests have the responsibility to assess to what extent the desperate character of certain situations may compromise the judgment of these people.

### Equality among people

Respect for human dignity requires that equality among all people be recognized. All human beings are born equal, and this fundamental principle is the basis of the Quebec Charte des droits et libertés de la personne (the Quebec Charter of Human Rights and Freedoms) and the Canadian Charter of Rights and Freedoms. Equality among persons is mainly relevant to reflection about preimplantation genetic diagnosis because of the possible consequences of selecting embryos with a view to preventing the birth of persons with particular diseases or carrying particular susceptibility genes.

Knowing that it is possible to diagnose a genetic disease, it is all-important to ensure that children born after such a diagnosis are not stigmatized, that support services offered to their parents are not reduced and that the integration of these people in society is not compromised. Similarly, some authors and caregivers are concerned about the possibility of a form of long-term stigmatization of people with such diseases. Furthermore, if PGD is becoming more efficient and more affordable, will a lot of research still be conducted on the treatment of genetic diseases?

Given the development and improvement of PGD, the Commission fears an eventual increase in social intolerance towards patients or people with severe disabilities. Could the very possibility of avoiding the birth of seriously ill persons or carriers of defective genes or susceptibility genes contribute to an increasingly demanding social redefinition of normality? Moreover, don't universal screening programs pose an indirect challenge to the value of equality among people by suggesting that society is willing to deploy significant resources to prevent the birth of people with a particular disease? Ultimately, embryo selection raises fears associated with any eugenic practice.

### Practice and ethical issues

PGD is considered a very early-stage PND, since it analyses the genetic heritage of one or two embryonic cells on day three of their development in order to transfer only healthy embryos. At the present time, these latest applications are steering away from the objectives and indications of PND and are generating the most ethical discussion. These applications aim to: increase the chances of successful IVF, ensure the health of the child, seek to benefit a third person, satisfy non-medical indications. In fact, however, clinical situations often make it hard to distinguish between these applications.

### Diagnosis aimed at increasing the chances of assisted procreation succeeding

It is worth remembering that in all *in vitro* fertilization, embryos are selected on the basis of observations to identify the embryos most likely to develop after implantation and to increase the chances of assisted procreation succeeding.

PGD could improve this selection by identifying embryos that are carriers of an abnormal number of chromosomes, resulting in the majority of cases in implantation failure or miscarriage. As a result, PGD could increase the chances of assisted procreation succeeding. This possibility remains open to debate, however, particularly regarding the benefits of using this technique in women who have experienced multiple miscarriages, have met with failure in previous AP attempts, or are at an advanced age. Several professional organizations agree that more research is needed to determine the true benefits and indications of this type of PGD use. Apparently, other procedures are currently in development which involve less risk to the parties concerned and do not require the removal of cells(s) from the embryo.

When compared to pregnancies resulting from natural conception, pregnancies resulting from IVF are associated with a higher risk of miscarriage, of prematurity (which leads to multiple consequences of varying degrees of severity for the child), of intra-uterine stunting, malformations or congenital diseases. Accordingly, if it proved possible to avoid such risks by undertaking PGD, and if the benefits of such a procedure were confirmed scientifically, then PGD could meet the basic requirements ensuring the well-being of individuals using AP and children resulting from the procedure. However, the Commission is particularly concerned about the prospect that if PGD were to become widespread, it would amount to systematic genetic screening of embryos with abnormalities such as trisomy 21, which raises major ethical and social issues. The Commission therefore stresses the importance of respecting the objectives of PGD, namely to improve the chances of assisted procreation succeeding, and reiterates the need to avoid slippage towards systematic screening of genetic conditions in pursuit of some other objective.

*Whereas PGD for the purpose of increasing the chances of success of AP is not a recognized and proven procedure and considering that current scientific controversies fully justify adopting a prudent approach, the Commission recommends:*

#### **Recommendation No. 12**

That PGD for the purpose of increasing the chances of assisted procreation succeeding be only offered:

- Where specific medical indications are met;
- As part of a research protocol which has been subject to scientific and ethical review.

## Diagnosis aimed at the health of the child

The main objective of preimplantation genetic diagnosis is the detection of genetic diseases or abnormalities with a view to avoiding the birth of children likely to develop diseases after birth. The ethical issues raised by PGD aimed at the health of the child vary, depending on whether monogenic diseases are at stake, recessive diseases, certain disease-susceptibility genes (for example cancer) and late-onset diseases.

### *The diagnosis of monogenic diseases*

This model of PGD is intended for couples or individuals who know they are at risk of transmitting a genetic defect to their children that causes genetic disease. PGD can be used to diagnose major monogenic diseases such as cystic fibrosis (or mucoviscidosis), spinal muscular atrophy, myotonic dystrophy (or Steinert's disease) and sickle cell anemia. The following sex-linked diseases may also be screened: Duchenne muscular dystrophy, hemophilia, adrenoleukodystrophy and Hunter syndrome.

A PGD procedure that makes it possible to select embryos not carrying the gene for a monogenic disease and to implant them into the uterus acknowledges the value of the child's well-being and the concern to respect the reproductive autonomy of individuals. This clinical intervention can prevent an unborn child from living with a disease that could significantly affect its quality of life. The Commission is motivated by a desire to strike a balance between the values of the child's well-being, individual liberty, dignity and the equality of persons, and accordingly proposes looking for a solution:

- that limits access to PGD, which would be offered to parents at risk of conceiving a child with a severe monogenic disease involving irreversible handicaps for the child;
- that offsets access to PGD by a strengthened commitment to ease the integration of persons with disabilities or suffering from these serious diseases, by means of social policies protecting their rights and promoting their integration into society.

It is no easy task to objectively determine the medical indications likely to justify PGD, since such a determination involves the concept of quality of life. As a way of mitigating the subjective nature of this concept, the Commission uses some inclusion criteria for determining which diseases are considered as medical indications for PGD: the severity of disease, its inevitability, its generally severely debilitating or fatal character, and the absence of treatment. This list of criteria is not exhaustive and some borderline cases may arise.

The existence of PGD raises the question about a parents' hypothetical *duty* to select embryos not carrying a disease, and therefore about their responsibility in this regard. Is it the responsibility of parents, clinicians or the State to determine the ethical acceptability of PGD, to specify indications and to select an embryo to be implanted? In the Commission's view, it is clear that society is involved and should therefore take part in these decisions.

*Whereas the collective determination of medical indications for PGD would ensure a balance between the privacy of a parental project, the responsibility of the parties with respect to the health and well-being of the child as well as respect for the equality and dignity of persons, the Commission recommends:*

### **Recommendation No. 13**

That access to PGD be open to couples or individuals with a known risk of conceiving a child with a serious, severely debilitating or fatal inherited monogenic disease, for which there is no known treatment.

*Also whereas it is difficult to determine how far the criterion of severity may be extended, without detailed consideration, the Commission recommends:*

### **Recommendation No. 14**

That the Minister of Health and Social Services grant a mandate to the Agence d'évaluation des technologies et des modes d'intervention en santé (AÉTMIS) to draw up a list of serious, severely debilitating or fatal monogenic diseases, for which there is no known treatment.

Moreover, while medical indications seem to justify embryo selection as a way of avoiding the birth of seriously ill children, a balance must be sought between respect for the dignity of persons living with disabilities and respect for the reproductive autonomy of prospective parents, including the possibility of preventing the birth of a child whose quality of life would be greatly and permanently diminished. It is therefore necessary to consider the possibility that a definition of PGD accessibility criteria could lead in the mid- or long-term to a certain collective standardization of the selection procedure for PGD access. The question of the social consequences that such criteria could have on indications at diagnosis go to the heart of debates about liberal eugenics – a form of discrimination against persons with long-term disabilities, and which would result from a standardized process of embryo selection.

*Whereas risks are associated with open access to PGD for specific medical indications, the Commission recommends:*

### **Recommendation No. 15**

That the Government of Quebec, in order to avoid eugenic practices, as well as discrimination against and stigmatization of people with genetic diseases or genetic abnormalities, improve and set up programs:

- To meet their needs and those around them and
- To promote the integration of these persons into society.

#### *The diagnosis of embryos that are heterozygous carriers of genes for a recessive disease*

While the Commission considers that it is acceptable to make PGD available in cases where the child may develop a serious genetic disease, it does not consider the diagnosis of embryos that are heterozygous carriers of genes for a recessive disease to be an equally acceptable justification for PGD. This diagnosis would be aimed at rejecting embryos carrying a recessive genetic mutation, that is, embryos not at risk of developing the disease after birth.

Yet, is it ethically acceptable to undergo PGD, for the primary purpose of rejecting such embryos and knowing they are unlikely to develop the disease? These children will not live with a serious, incurable and disabling illness. They will have to make reproductive choices in adulthood, in the event that their spouse also carried the same genetic abnormality, but they will have access to PND and eventually to PGD, or may be able to seek alternatives such as adoption or gamete donation.

*Whereas this is a situation where the costs outweigh the benefits that would like accrue to society as a whole and to individuals from such an indication for PGD, the Commission recommends:*

### **Recommendation No. 16**

That access to preimplantation genetic screening not be permitted for the sole purpose of screening embryos that are heterozygous carriers of a recessive disease, that is to say, in cases where one parent is a heterozygous carrier of such a disease.

#### *The diagnosis of susceptibility genes*

The analysis of susceptibility genes aims to identify embryos with a gene predisposing them to develop a disease during their lifetime.

The child carrying the susceptibility gene will not necessarily suffer from the disease in question, because these diseases are multifactorial, that is they are not only caused by a genetic predisposition, but result from a combination of several genes and factors such as the environment, diet, smoking and other lifestyle habits.

This is therefore a matter of screening rather than of diagnosis, since the idea is not to be *certain* that the child will actually have the disease, but rather to *estimate the risk* that the child will develop the disease in adulthood. Alzheimer's disease is often mentioned in this category.

The ethical acceptability of this form of PGD will depend on the justification for resorting to embryo selection, taking into account the *risk* of developing serious illness. According to current thinking, it is more probable that multifactorial diseases will be prevented by adopting healthy lifestyles in a healthy environment than by using PGD to screen for susceptibility genes.

*Whereas in the present state of knowledge, this type of disease – including some cancers such as breast cancer – cannot be classified in the same category as diseases constituting indications for PGD, the Commission recommends:*

### **Recommendation No. 17**

That preimplantation genetic diagnosis not be used to screen an embryo with susceptibility genes to multifactorial diseases.

#### *Diagnosis for the benefit of the health of a third party*

A recent application of PGD consists in developing an *in vitro* embryo, which on the one hand is not a carrier of a genetic disease and on the other is selected for histocompatibility lymphocyte antigen (HLA), so that it is immunologically compatible with a brother, sister or sick relative whose survival depends on marrow or stem cells extracted from umbilical cord blood. In the case of this application, the indication for PGD is the desire to conceive and select an embryo destined to become a donor, hence the designations “designer baby”, “saviour child”, “donor baby”, or “double hope baby”.

Since the chances of success are very slim, couples often have to go through several cycles of *in vitro* fertilization. Moreover, for this procedure to succeed (it requires the birth of a compatible donor), the sick child needs to be able to survive long enough for the IVF procedure to be performed and the pregnancy to be carried to term (minimum one year).

In the context of this type of indication for PGD, the question arises whether the implanted embryo is selected solely because it will not develop serious illness, but also because it has a genetic characteristic making it suitable as a donor of cells from cord blood cells or bone marrow for the benefit of a family member.

The main concerns expressed about the welfare of the child arising from this practice include, among others, its psychological development and its identity. In this situation, the Commission places the values of dignity and respect for the symbolic freedom of the child at the core of its reflection, and also highlights the negative physical and psychological changes that may affect the actors involved.

From the outset, conceiving a child in order to meet the therapeutic needs of a family member necessarily constitutes a form of instrumentalization; the Commission cannot support such a practice. The Commission believes that approving of this kind of “reparative medicine” would amount to allowing for the production of human beings without any consideration for their dignity.

The selection of embryos based on their immunogenetic compatibility also runs the risk of undermining the symbolic freedom of the child: in such cases, the resulting child would be “determined” by the willingness of its parents that it assume a specific role, which constitutes a violation of its physical integrity.

Due consideration should also be given to the psychological risks for the child and for the construction of its personality, when it has been conceived in fulfilment of a “therapeutic” role which its parents want it to play in its family. How will the child perceive itself? What happens if it is not successful in playing the therapeutic role assigned to it? What seems especially threatening in this practice is that this human being carries the psychological burden within the family of representing THE therapeutic solution to a desperate situation.

Physical discomfort may also occur. Insofar as the donation of cells from cord blood involves no risk or discomfort for the infant, the question of the subjection of the designer baby arises more on the mid- to long-term if it were deemed necessary to remove more bone marrow.

*Whereas there are risks to the value of respect for the dignity of the child and its welfare, as well as physical and psychological risks to stakeholders, and whereas the bank of umbilical cord blood managed by Héma-Québec is a promising alternative to help sick children, the Commission recommends:*

#### **Recommendation No. 18**

- That the use of preimplantation genetic diagnosis for the selection of embryos be prohibited where the primary motivation is to conceive a donor of tissue or stem cells;
- That the collection of umbilical cord blood be encouraged in order to supply the public bank managed by Héma-Québec.

#### **Diagnosis for non-medical reasons**

Non-medical reasons prompting people to resort to PGD are: wanting a child with a particular disability, sex selection of a child or ensuring that it is born with specific characteristics.

##### *The birth of children with disabilities*

Preimplantation genetic diagnosis allowing the selection of embryos carrying an illness or disability aims to satisfy the wishes of those who are themselves suffering from this disability or illness, and who want to share this health status with their child. The Commission has focused particularly on the case of a couple of deaf women who made every effort to conceive a deaf child through self-insemination using sperm from a deaf donor. This situation was not an indication for PGD. However, it is quite possible that clinics performing PGD receive requests of this sort, and that clinical teams suffer some discomfort as a result. This choice was based on a current of thought according to which deafness is not a handicap, but is rather a cultural identity.

This parental choice would only be acceptable if it were based on the well-being of the child. Yet, if parents believe that the welfare of their child necessarily depends on being part of the family unit and the existing culture with respect to the disability in question, then it is difficult to deny them access to genetic selection on the basis of disability. The child, however, may be locked into a difficult psychological or existential paradox: if the child does not accept the state chosen for it by its parents, then it denies its own existence. This paradox is all the harder to bear, since it results from a deliberate parental choice.

The Commission recognizes that requiring couples or individuals using PGD to have only healthy children would amount to a new form of State eugenics which the Commission cannot endorse. Such a practice would be contrary to the values of equality and respect of human dignity to which the Commission fully subscribes.

Given the complexity of the problem and to need to reconcile conflicting values, the Commission believes nonetheless that access to PGD should not be offered to couples who from the outset seek to give birth to a child with a disability, while no restriction should be imposed on the genetic status of implanted embryos, once PGD has been performed.

#### *Sex selection*

Some parents use PGD in order to choose the sex of the child when they are carriers of an X-linked disease, such as hemophilia, which develops most often in boys and more rarely in girls. In such cases, sex selection is motivated by purely medical reasons. However, the Commission considers that the possibility of choosing the sex of a child for cultural, personal, or socio-economic reasons is an entirely different matter.

There does not seem to be any consensus in this area. Some people hold that sex selection for non-medical reasons should not be encouraged, whereas they deem it acceptable to sort sperm for the purposes of “family balancing”. It should be noted that American clinics appear to offer the service of sex selection for non-medical reasons, but only to people using PGD for medical reasons; sex selection is thus presented as an additional option.

#### *The choice of specific characteristics*

The Commission wonders about the issue of selecting embryos with certain characteristics particularly favoured by prospective parents. This type of selection is sometimes referred to as production of “customized babies”, given the subjective nature of indications. The choice may involve physical or psychological traits. Science does not seem able to meet these expectations for the time being, but it is clear that some demand for the selection of genetic characteristics based on reasons of so-called convenience could develop in the future.

For the Commission, the conception of human dignity is undermined by the prospect of a world where parents choose the physical and psychological traits of their child. The prospect of such selection reflects the fact that instrumentalization of the unborn being clearly depends on the parental wish to select a child that satisfies their desire.

*Whereas preimplantation genetic diagnosis for non-medical reasons is unacceptable ethically, because it conflicts with respect for the symbolic freedom of the child, and opens the door to choices about specific characteristics that may not pose a risk to the health and well-being of children, but nevertheless would undermine human dignity, the Commission recommends:*

#### **Recommendation No. 19**

That the use of preimplantation genetic diagnosis be prohibited for the production of “customized babies”, based on non-medical indications, *and that* the use of preimplantation genetic diagnosis be prohibited:

- When the goal is the deliberate production of a child with disabilities or handicaps;
- When sex selection of a child is based on cultural, religious, personal or socio-economic reasons.

In a society that values autonomy, freedom of choice, and that emphasizes individual rights, questioning the legitimacy of the requests that citizens make of the State can be a delicate matter. Even so, this is precisely what the Commission has had to do, in the present position statement, in fulfilment of a mandate entrusted by the Quebec Minister of Health and Social Services. In the field of assisted procreation, the requests of infertile people or of those carrying genes for inherited genetic diseases are often perceived as distress calls. It should be noted that from the point of view of people articulating the desire to have children, this desire can easily become a fundamental need. While considering that having children is a privilege rather than a right, the Commission expresses its empathy for people who encounter significant problems conceiving naturally, without medical assistance. However, as moving as the requests for medical assistance may be, they must also be acceptable in societal terms. This is why the Commission has drafted recommendations and is offering guidelines which in ethical terms serve the public welfare; not all recommendations or guidelines will be universally approved, but the line of argument offered by the Commission may nevertheless contribute to public debates.

Each of the three issues discussed – gamete and embryo donation, surrogacy and preimplantation genetic diagnosis – could form the subject of a position statement on its own. Other issues would have profited from more detailed discussion, such as *in vitro* fertilization, prenatal diagnosis, eugenics, and filiation, just to name a few. The Commission hopes, however, that this position statement will contribute to advancing reflection which is now needed more than ever, and to inform Quebec legislator on the matter.







APPENDICES



## THE CONSULTATION ACTIVITIES OF THE COMMISSION AND CONTRACTED RESEARCH WORKS

### The following organizations and individuals made submissions:

M<sup>e</sup> Caroline Amireault, *Association des couples infertiles du Québec*  
Ms. Véronique Bergeron and Mr. Patrick Lavoie, *in their role as citizens*  
Ms. Nathalie Boëls, *Spina Bifida and Hydrocephalus Association of Québec*  
Ms. Mariangela Di Domenico, *Conseil du statut de la femme*  
Mr. Steve Foster, *Conseil québécois des gais et lesbiennes*  
Ms. Beverly Hanck, *Infertility Awareness Association of Canada*  
Dr. Yves Lamontagne, *Collège des médecins du Québec*  
Dr. Corinne Leclercq, *Association of Obstetricians and Gynecologists of Québec (AOGQ)*  
Ms. Nathalie Parent, *Fédération du Québec pour le planning des naissances*

### Online consultation on assisted procreation, from 3 September to 3 October 2008

**Number of participants:** 1,066

**Women:** 82.36%; **Men:** 17.64%

**30 to 44 years of age:** 50.09% ; **18 to 29 years of age:** 32.83%

**Regions:** Montréal (27%), Québec (21%), Montérégie (14%), Laurentides (4-5%),  
Chaudières-Appalaches (4-5%), Estrie (4-5%), Laval (4-5%), Lanaudière (4-5%), Mauricie (2-  
3%), Outaouais (2-3%), Saguenay (2-3%), Abitibi-Témiscamingue (2-3%) et Centre du  
Québec (2-3%)

**University degree (either completed or currently underway):** 63%

**French (language spoken in the home):** 96%

**Have a children by natural birth:** 45% ; **Adopted child:** 5% ; **Have tried AP:** 21%

**Women having been solicited to bear a child for a couple:** 12 women

**Men having donated sperm:** 7 men

**Women having donated ovules:** 4 women

**The following people spoke during audiences of the working committee:**

**25 September in Montréal:**

Ms. Chantal Bouffard, *Anthropologist and professor at Université de Sherbrooke*  
Ms. Valérie Désilets, *Medical geneticist at Hôpital Ste-Justine*  
Ms. Beverly Hanck, *Infertility Awareness Association of Canada*  
Dr. Michèle Marchand, *Collège des médecins du Québec*

**26 September in Montréal:**

Ms. Nathalie Bolduc and Ms. Andrea Secord,  
*Genetic counsellors at the Montreal Children's Hospital*  
Dr. Robert Hemmings, *The Society of Obstetricians and Gynecologists of Canada*  
Dr. Karine Igartua, *Psychiatrist at the McGill Sexual Identity Centre*  
Ms. Louise Vandelac, *Sociologist and professor at the Université du Québec à Montréal*

**3 October in Québec:**

Ms. Carole Tardif and Ms. Sandra Villeneuve, *Association pour l'intégration sociale*  
Mr. Bernard Keating, *Professor in the Faculty of Theology at Université Laval*  
Mr. Thomas De Koninck, *Professor in the Faculty of Philosophy at Université Laval*  
M<sup>e</sup> Anne-Marie Savard, *Lawyer specializing in the rights of the person*

**The Commission granted short-term contracts to the following people:**

Ms. Marie-Pier Barbeau  
Ms. Valérie Bouchard  
Ms. Cynthia Pratte  
Ms. Renée Dolbec (for the French linguistic revision of an additional document)

**The Commission thanks all of these people for their contribution to developing and enhancing the content of its position statement on assisted procreation.**



## MEMBERS OF THE COMMISSION<sup>442</sup>

### PRESIDENTE

#### **M<sup>e</sup> Édith Deleury**

Professor Emeritus – Faculty of Law  
Université Laval

### MEMBERS

#### **Patrick Beaudin**

Director General  
Société pour la promotion de la science  
et de la technologie

#### **Dr Pierre Deshaies**

Specialist in community health  
Head of the Clinical Department of Public Health  
Hôtel-Dieu de Lévis

#### **Hubert Doucet**

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#### **Benoît Gagnon**

Associate researcher  
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Identity and Technology  
Université de Montréal

#### **Mariette Gilbert**

President  
Association féminine d'éducation et d'action sociale

#### **Jacques T. Godbout**

Sociologist  
Institut national de la recherche scientifique –  
Urbanisation, Culture et Société

#### **Françoise Guénette**

Independent journalist

#### **Patrice K. Lacasse**

Social development coordinator  
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### SECRETARY GENERAL

#### **M<sup>e</sup> Nicole Beaudry**

<sup>442</sup> When the present position statement was adopted.



