

Ethical Guidelines on Pre-implantation Genetic Diagnosis (PGD)

General Principles

1. Pre-implantation genetics diagnosis (PGD) is a technique that may be used to combine IVF and genetic testing as a means of avoiding the transmission of a genetic abnormality or a disease. PGD must be conducted in accordance with the following basic ethical principles -

- (a) human life in all its forms warrants respect and special moral consideration;
- (b) the welfare of the child is of paramount importance;
- (c) personal autonomy, individual liberty and human integrity must be duly safeguarded;
- (d) basic community values such as responsible parenthood, parental love and the family should be recognized; and
- (e) use of resources must be based on the principles of care, equality, justice and accountability and a reasonable balance must be sought between individual and collective interests to protect vulnerable parties from harm or exploitation.

Application of PGD

2. PGD should only be used for the detection of serious genetic conditions or abnormalities that significantly affect the health of an individual who might be born. Due attention should be given to the differing views in society about seriousness of genetic conditions or abnormalities, and the potential development in medicine that may shift the boundaries defining seriousness of genetic conditions or abnormalities.

3. PGD should not be used with the intention to enable parents to select a baby with some desired social, physical or psychological characteristics.

Preparation for PGD Procedures

4. The use of PGD should be a matter of discussion between those seeking PGD (i.e. the parents) and the clinical team on the seriousness of the genetic condition or abnormality and their experience and perception of abnormality.

5. The clinical team should consist of 2 doctors, one of whom should have proper training in clinical genetics and/or genetic counselling.

6. The clinical team, having discussed with the persons seeking PGD and determined the condition to be sufficiently serious to warrant PGD, need to provide the Council with a report within 3 months after completion of the procedure, detailing -

- (a) the nature of the genetic condition/abnormality;
- (b) the likely effect of the genetic condition;
- (c) the anticipated risk of transmission; and
- (d) the effectiveness of the testing.

7. The clinical team should follow the detailed reporting requirements as specified under the Human Reproductive Technology Ordinance, its regulations, and the legal notices and government notices issued from time to time by the Council on Human Reproductive Technology.

8. It is also necessary for the clinical team to provide the person seeking PGD with appropriate counselling and adequate information on the other genetic testing options.

Tissue Typing in Conjunction with PGD

9. In addition to using PGD for genetic diagnosis to avoid serious genetic diseases, PGD can be used together with histocompatibility leukocyte antigen (HLA) tissue typing to identify embryos which match a living sibling with a genetic condition, with the intention that when the matched embryo develops into a baby, blood can be harvested from its umbilical cord to provide stem cells for transplantation to the sibling. Practitioners who intend to undertake PGD together with HLA have to seek prior approval from the Council on a **case by case basis**. Only applications for the harvest of cord blood or bone marrow would be considered, and the harvesting of non-regenerative organs is not acceptable. Tissue typing in conjunction with PGD would be considered case by case with regard to compliance with the following basic ethical principles -

- (a) all other possibilities of treatment and existing sources of tissue for the affected child should have been explored;
- (b) the condition of the affected child should be severe or life-threatening;
- (c) the parents cannot be the intended tissue recipient and the primary intended tissue recipient should be a sibling;
- (d) embryos should not be genetically modified to provide a tissue match; and
- (e) appropriate pre-treatment and follow-up counselling should be provided to the couple to whom treatment is provided or intended to be provided. The counsellor should clearly explain to the couple that if the child is wanted for his/her own worth, the treatment might be justifiable. If the child is conceived solely for the purpose of creating a donor of stem cells for an existing sibling, the child's dignity is violated and the treatment is not justifiable.

10. Implications counselling should be provided by the centres offering pre-implantation tissue typing and the following factors should be considered -

- (a) the motivation and level of understanding of the parents (in particular the woman undertaking the IVF treatment) seeking to have additional child;
- (b) the condition of the existing child such as the degree of suffering associated with the condition of the affected child, the prognosis for the affected child in relation to all treatment options available;
- (c) the possible consequences of the child to be born (such as the risks associated with embryo biopsy for the child to be born, the likely long term emotional and psychological implications for the child to be born, whether the treatment of the affected child is likely to require intrusive surgery for the child to be born);
- (d) the family circumstances of the people seeking treatment such as the

- perception of the family on the consequences of the unsuccessful outcome, the issue which might arise when the birth of a child does not resolve the genetic condition of the existing child; and
- (e) the extent of social support available.

11. A clinical report in addition to that mentioned in para. 6 should be submitted to the Council with the application for the tissue typing procedure which should include the details of the condition of the existing child, prognosis for the affected child in relation to all treatment options available and evidences showing that the guiding principles of the above are strictly followed.