Genetic Testing of IVF Embryos

A new report by European Commission scientists gives a full picture of preimplantation genetic diagnosis (PGD). Parents need better information on genetic testing of IVF embryos.

A new report by European Commission scientists shows that urgent guidelines are needed for the counselling of patients that opt to screen their embryos created by in vitro fertilisation (IVF) for serious genetic disorders, and there is a need for specific quality assurance schemes. Preimplantation genetic diagnosis (PGD) is the practice of testing embryos for conditions such as Huntington's, haemophilia and cystic fibrosis before they are implanted in the mother. As the first report to give a full picture of this practice at European level, it shows that PGD is a well-established practice in many Member States, but regulations, standards and accreditation requirements can differ widely. The report, drawn up by the Commission's in-house scientific service, the Joint Research Centre, in co-operation with a number of European research centres, will help provide more knowledge and information about current PGD services.

The main findings of this study result from a survey submitted in 2006 to over 160 centres across Europe potentially performing PGD. The survey identified 53 centres offering PGD in 16 EU countries and Switzerland, most of them located in Spain, Belgium, Czech Republic, Greece and the United Kingdom. In a later stage, to deepen and sharpen the survey's results, the authors of the study held nearly 30 interviews with PGD specialised personnel of these centres.

Some of the report's main conclusions are:

- PGD is an expanding activity in Europe with increasing social implications.
  Patients travel within Europe for PGD, mostly for legal and financial reasons but also because of (non-)availability of the test at home.
- The sources of information used by parents when accessing a preimplantation diagnosis treatment in another country vary. In some cases, the main sources are
  websites of in vitro fertilisation (IVF) clinics, other parents previously treated and medical genetics services of the country of origin.
- 94% of the centres require the informed consent of the patients and offer genetic counselling, although it is not clear whether such counselling is actually given.
- Results show that only half of the clinics and laboratories have a quality manager among their staff and, although the majority of centres rate external quality assessment as relevant, only one third of them actually participate in external quality schemes.
- At EU level, the most significant legislation affecting PGD provision and regulation is the Human Tissue and Cells Directive (Directive 2004/23/EC of 31 March 2004), which introduces a wide range of quality and safety requirements
  that clinics have to implement and which had to be brought into force by Member States not later than 7 April, 2006.

The full report can be downloaded from this site as a PDF file.

Preimplantation Genetic Diagnosis in Europe - Executive Summary (PDF, 107.42 KB)

Preimplantation Genetic Diagnosis in Europe (PDF, 1.88 MB)

Press release

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