

Expert briefing notes

Science briefing

The technique referred to is preimplantation genetic diagnosis (PGD). This is used in combination with in vitro fertilisation (IVF) to screen for several different genetic conditions.

The main use is to screen for diseases including Huntington's disease, cystic fibrosis and more recently Down's syndrome.

The first stage of PGD involves creating embryos by IVF. A cell is then removed from each of the early stage embryos to identify which ones carry the disease. Only 'good' embryos are placed in the mother's body to develop.

Effectiveness

There is a 98% chance that an embryo selected in this way will be a tissue match. In this particular case there is only a 1 in 4 chance that the couple would have a baby that matches if doctors and nurses did not use the new technique.

Uncertainty/Risks

- After the baby is born, is there a chance that the baby will not be a match?
- Is the IVF procedure completely safe?

Ethics briefing

- Is it like treating the offspring as a commodity?
- Is it fair to subject a child to a lifetime of donating the cells to a sibling? Would this actually be the case?
- How would the parents regard the new child if the technique failed?
- Should more effort and investment be put into finding alternatives or compatible tissue donors?
- Who benefits most?

Law briefing

In the UK, the use of embryos is strictly regulated by the Human Fertilisation and Embryo Authority (HFEA).

The HFEA is a non-departmental Government body that regulates and inspects all UK clinics providing IVF, donor insemination or the storage of eggs, sperm or embryos. The HFEA also licences and monitors all human embryo research being conducted in the UK.

Clinics wanting to carry out this procedure have to apply to the HFEA for a licence to do it.

The Human Fertilisation and Embryology Authority said it was acceptable to test and select embryos to prevent the birth of a baby with a genetic disease, but not to select solely in order to help another child.

It must be stressed that the applications are considered on a case-by-case basis, and subject to strict conditions.

Law briefing

Recently, a family in a similar situation were refused permission to go ahead with the treatment in the UK. So, they travelled to the USA for treatment.

The child was born in summer 2003 and did provide a tissue match. Treatment on the older child is now in progress.

There was a similar case this year but there was a significant difference between the two cases. The Human Fertility and Embryology Act 1990 allows genetic selection of embryos if it is in the child's interests i.e. if there is any risk that they will be born with a specific disease. In the second case, there was a greater chance that the newborn baby would inherit the genetic illness and there was also a genetic marker to check this. Genetic markers are pieces of DNA contained in a cell that can be used to test if a genetic disorder is present.

The Human Fertilisation and Embryo authority said it was acceptable to test and select embryos to prevent the birth of a baby with a genetic disease, not to select them solely for the benefit of another child.

The HFEA has stressed that applications will be considered on a case by case basis, and subject to strict conditions.