

The Genetic Interest Group (GIG) welcomes the Human Fertilisation & Embryology Authority's review of the case by case approach to the licensing of preimplantation genetic diagnosis (PGD). Given the Human Fertilisation & Embryology Act as amended, GIG does not see any need to revisit the debate regarding appropriateness of PGD or preimplantation tissue typing.

GIG supports condition-by-condition licensing of conditions for both PGD for late onset conditions and for preimplantation tissue typing of embryos.

PGD for late onset conditions

- The time delay imposed by using a case-by-case licensing process instead of a condition-by-condition licensing process is especially harmful for patients with some late onset conditions. The risk of the late onset condition manifesting during the treatment process should be considered, and women with BRCA1 for example may be considering preventative oophorectomy.
- The age of onset and severity of expression is impossible to predict. When conditions with incomplete penetrance, and varying age of onset and expressivity, are considered for licensing, the worst possible case that can be reasonably expected should be the scenario under which the resulting child will be expected to live.
- The "treatability" of these conditions should not be considered as an argument against the use of PGD to prevent affected births, except where such a treatment will be minimally invasive, and allow the affected child to expect a normal life free from restriction. None of the late onset conditions currently licensed for PGD have such treatments available.

Preimplantation tissue typing of embryos

- The time delay imposed by using a case-by-case licensing process instead of a condition-by-condition licensing process is especially harmful for families with a sick child who could benefit from a sibling donation of cells or tissue. The affected sibling may have a very short life expectancy. To maximise chances of success of such donation delays should be minimised.

GIG sees no constructive benefit gained by maintaining case-by-case licensing for either PGD for late-onset conditions or PGD involving tissue typing. GIG believes that both of these types of PGD should be licensed on a condition-by-condition basis for the reasons outlined above.