



Authority decision on the use of PGD for lower penetrance, later onset inherited conditions

The Human Fertilisation and Embryology Authority (HFEA) has considered the use of preimplantation genetic diagnosis (PGD) for inherited, lower penetrance, conditions (conditions that only manifest in a subset of the people that inherit a faulty copy of a particular gene). The conditions in question are primarily caused by a fault in one specific gene (single gene disorder) and although other factors may contribute, the presence of the faulty gene significantly increases the chance of an individual developing a serious disease such as cancer.

The Authority recognises that inherited forms of these diseases are rare (less than 10 per cent of cases of breast and bowel cancer are thought to be inherited). Carrying the faulty gene can cause significant anxiety which is not lessened by the fact that the condition is not fully penetrant. The Authority considers conditions of this type to be serious genetic conditions. It also recognises that the impact of carrying a gene that increases risk of developing a given condition differs between individuals. The impact can differ both in terms of how an individual might perceive the risk as well as, more practically, the way that the condition will manifest in any particular family. Therefore the Authority considers it essential that the views of the individuals seeking treatment be taken into account in the decision making process.

Taking into account the range of views expressed in the public discussion and the recommendations of the Ethics and Law Committee, the Human Fertilisation and Embryology Authority believes that, in principle, it is appropriate that PGD be available for serious, lower penetrance, later-onset genetic conditions such as inherited breast, bowel and ovarian cancer. This decision does not fetter the discretion of a Licence Committee which will consider the individual merits of each application.

The Authority decided that applications for lower penetrance conditions should initially be considered on a case-by-case basis because of the difference in the way that families are affected by these conditions and also because this is a new class of PGD conditions. This will be reviewed in two years when the Authority has more knowledge and experience of dealing with such applications.