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A justifiable alternative; Medical Ethicist

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The granting of a licence to avoid the birth of children carrying the retinoblastoma gene marks another direction for pre-implantation genetic diagnosis (PGD). Selection is no longer against disease, but susceptibility. A child born with retinoblastoma will not definitely fall ill. There are treatments to control it in its early stages. But this does not mean we should not offer PGD for retinoblastoma.

PGD to avoid the birth of children with genetic diseases has public support, for good reason. Retinoblastoma is an especially unpleasant disease. It can lead to blindness or death, and treatment often requires chemotherapy and removal of the eye. This is why prenatal diagnosis in early pregnancy is offered. Yet this is not an ideal option. A woman may not want to abort on the chance that her child might get cancer. There is also no guarantee that the next pregnancy will be healthy.

PGD therefore offers a real alternative. The gene is not passed on but no abortion is required.

Often overlooked in these debates is the "lived experience" of genetic disease.

For the couples seeking PGD, retinoblastoma is life-affecting enough for them to undergo an invasive, lengthy and draining medical procedure. If avoiding this disease is justifiable, it is worth offering PGD.

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