

Preimplantation Genetic Diagnosis (PGD): Conditions licensed by the HFEA

Updated January 2009

What is PGD?

PGD is a technique that helps people avoid passing on an inherited disease or condition to their children. It involves creating embryos through IVF and testing those embryos to see if they have the genetic defect that is known to cause the inherited condition. The embryos that do not have the genetic defect may then, as with conventional IVF, be transferred to the womb or frozen for transfer later.

Where do I start?

If you are considering PGD, you should first talk to your GP about the options available. Your GP can also refer you to see a specialist at a hospital or fertility clinic.

Your clinician will be able to advise you about whether PGD is possible and appropriate for you. Clinics must consider every patient individually and PGD will not be suitable or possible for every patient.

Which clinics offer PGD?

Clinics must have an HFEA licence to carry out PGD. In addition, a clinic must be licensed for each specific condition it wishes to test for. If your chosen clinic already has a PGD licence, but is not currently licensed to test for a condition, it may apply to the HFEA to add that condition to its licence.

To find clinics that offer PGD, see our “At A Glance” downloadable guide (PDF):
<http://guide.hfea.gov.uk/guide/pdf/AtAGlance.pdf>

Which conditions can PGD be used for?

Most of the conditions currently licensed by the HFEA are shown in the list below. However, a condition might not be included here because:

- **there is a risk of patient identification.**
A handful of conditions are so rare that, if we listed the condition here, the family may be identified by others.
- **the condition is not yet licensed or was licensed after this list was published**
Clinics can apply to the HFEA to have conditions added to their licence. PGD is an area of medicine that is rapidly developing, so new tests become available regularly.

‘Case by case’ licences

Most conditions are licensed so that a clinic can carry out PGD for any patient who requests it, so long as there are good clinical reasons for doing so.

However, there are a small number of conditions which the HFEA only licenses on a case by case basis. For these conditions, the clinic must apply to the HFEA for a special licence to carry out the test for a specific patient.

Your clinician will be able to advise further.

For more information about PGD, see www.hfea.gov.uk

Please note: This list shows most but not all of the conditions currently licensed by the HFEA for PGD testing. Some are not included here because their rarity means there is a risk of patient identification. Read the FAQs on the first page of this document for further information.

- Adrenoleukodystrophy
- Agammaglobulinaemia
- Alpers Syndrome
- Anderson Fabry Disease
- Androgen Insensitivity Syndrome
- Autosomal recessive non-syndromic sensorineural deafness
- Beckers Muscular Dystrophy
- Beta Hydroxyisobutyryl CoA Hydrolase Deficiency (Methacrylic Aciduria)
- Beta Thalassaemia
- Breast cancer, BRCA 1
- Bruton Agammaglobulinemia Tyrosine Kinase (BTK)
- Cardiac Valvular Dysplasia
- Charcot Marie Tooth Disease
- Choroideraemia
- Chronic Granulomatous Disease
- Coffin-Lowry Syndrome
- Congenital Adrenal Hyperplasia
- Congenital Fibrosis of the Extraocular Muscles
- Crouzon Syndrome
- Cystic Fibrosis
- Duchenne Muscular Dystrophy
- Early Onset Alzheimers Disease
- Ectodermal Dysplasia
- Facioscapulohumeral Dystrophy
- Familial Adenomatous polyposis coli (FAP)
- Fanconi's Anaemia A
- Fanconi's Anaemia C
- Fragile X Syndrome
- Gonadal mosaicism
- Haemophilia A
- Haemophilia B
- Hallipeau-Siemens recessive dystrophic epidermolysis bullosa
- Homozygous familial hypercholesterolaemia
- Hunters Syndrome
- Huntington's Disease (Huntington's Chorea)
- Hydroxyisobutyryl CoA Hydrolase Deficiency
- Hypogammaglobulinaemia
- Incontinentia Pigmenti
- Infantile Battens Disease

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- Juvenile Retinoschisis
- Lenz syndrome
- Lesch Nyan Syndrome
- Li-Fraumeni Syndrome
- Lymphoproliferative Syndrome
- Marfan Syndrome
- Marfan Syndrome
- Metachromatic Leukodystrophy
- Multiple Endocrine Neoplasia Type 1
- Myotonic Dystrophy
- Myotubular myopathy
- Myotubular atrophy
- Neurofibromatosis type I
- Neurofibromatosis type II
- Niemann Pick Disease Type C
- Ornithine carbamoyl transferase (OTC) Deficiency
- Osteopathia Striata with Cranial Sclerosis (OSCS)
- Otopalatodigital syndrome type 2
- Partial Lipodystrophy, Familial, Type 2
- Pelizaeus Merzbacher Disease
- Prader Willi Syndrome
- Severe aplastic anaemia
- Severe Combined Immune Deficiency
- Sickle Cell Anaemia
- Spinal Muscular Atrophy
- Tay Sachs disease
- Treacher Collins Syndrome
- Von Hippel Lindau (VHL) Syndrome
- Wiscott-Aldrich Syndrome
- X-linked Hereditary Motor and Sensory Neuropathies
- X-linked hydrocephalus
- X-linked Immuno-deficiencies
- X-linked Mental Retardation
- X-linked spastic paraplegia
- Chromosomal rearrangements – PGD is also available for some chromosomal rearrangements.

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