

How much does PGD cost?

From April 2008, the cost of each PGD treatment cycle at Guy's Hospital is £5,850 plus the cost of the fertility drugs (approximately £1000-£1200). Over 75% of patients receive funding for their treatment from their Primary Care Trust, whilst the remainder of patients would have to self-fund. If you decide to pursue PGD, we usually apply for funding on your behalf. PCTs will usually not fund treatment if a couple have a living healthy child.

What else is there to consider?

- Having PGD is a relatively complicated and lengthy procedure. It takes approximately 8 months between your first PGD appointment and the start of treatment. It will involve about 4 hospital appointments per cycle.
- There are risks associated with having PGD treatment, e.g. hyperstimulation of the ovaries where the ovaries become very large and fluid may accumulate which may also cause abdominal swelling. This can lead to admission to hospital.
- Some women have a poor response to the fertility drugs and therefore there are no eggs for collection. There is the chance that no embryos will grow or there may be no unaffected embryos.
- There is a small risk of an error occurring in the testing. This will be discussed with you in greater depth if you pursue PGD.

- Whilst we believe that PGD is relatively safe, it is still a new technique and so all babies born as a result of PGD are followed up carefully.
- PGD can be a very emotionally and financially demanding process to go through.

How do I get referred to the PGD clinic?

To be referred to the PGD clinic, please ask your geneticist or genetic counsellor to refer you for an initial discussion appointment. This appointment will give you the opportunity to ask questions and find out more about PGD before reaching your decision. This appointment is free of charge.

For more information:

If you need more information or to make a referral please contact:
PGD Team
Clinical Genetics Department
7th Floor, Borough Wing,
Guy's Hospital, Great Maze Pond,
London SE1 9RT
Telephone: 020 7188 1364
Facsimile: 020 7188 1369
Website:
<http://www.guysandstthomas.nhs.uk/services/managednetworks/genetics>
www.pdg.org.uk

Factual information presented in this communication is based on accurate contemporaneous peer reviewed literature. Evidence of sources can be provided on request.

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Seen in clinic by.....

Preimplantation Genetic Diagnosis (PGD)



An Information leaflet

Introduction

Preimplantation genetic diagnosis (PGD) is a technique that is designed to help couples who are at risk of having a child with a serious genetic condition. PGD can also sometimes help couples who have had recurrent miscarriages because of a genetic condition.

This leaflet will provide you with some general information about PGD, in order to help you reach a decision about whether or not you would like to pursue this option.

What is Preimplantation Genetic Diagnosis (PGD)?

PGD involves using IVF (in vitro fertilisation) to create embryos in the laboratory from the eggs and sperm of that couple. Each embryo is then tested for the particular genetic disorder (this is called cell biopsy). One or sometimes two unaffected embryos are then transferred into the womb, in the hope that a pregnancy will occur.

Who can have PGD?

PGD is currently only offered in a few centres in the UK. The largest and most active PGD centre is based here at Guy's Hospital.

Our PGD centre is able to offer PGD for the following conditions:

- Chromosome rearrangements (including translocations, deletions and inversions)
- X-linked disorders (some limited to sexing the embryos)
- Rett syndrome
- X-linked hydrocephalus

- 22q deletion syndrome
- Duchene and Becker muscular dystrophy
- Myotonic dystrophy
- Fragile X syndrome
- Spinal muscular atrophy
- Cystic fibrosis
- Sickle cell disease
- Huntington disease
- Epidermolysis Bullosa (2 types)
- Incontinentia pigmenti
- VHL
- Adrenoleukodystrophy

What does PGD involve?

Even though most couples who are going to have PGD are able to become pregnant themselves, they will need to undergo in vitro fertilisation (IVF) to produce embryos for testing.

First, the ovaries of the female partner are stimulated to produce several eggs. This is achieved by using a combination of fertility drugs, which are taken by nasal spray and by daily injection.

Once the eggs are mature, they are collected from the ovaries under ultrasound guidance. A fine needle is passed through the vaginal wall to collect the eggs one by one. The procedure is carried out under deep sedation and usually takes around 20 minutes.

A semen sample is produced by the male partner on the same day.

The sperm are then used to fertilise the eggs in the laboratory. The sperm may be mixed together with the eggs (IVF), or a technique called intra-cytoplasmic sperm injection (ICSI) may be used.

Eggs which are successfully fertilised begin to grow and divide. They are now called embryos.

Three days later, once the embryo has grown to at least 6 cells in size, one cell is very carefully removed (this is called the embryo "biopsy").



This cell is then tested for the particular genetic condition.

The following day, one or sometimes two unaffected embryos are placed into the womb using a fine tube or catheter.

10 days later a pregnancy test is carried out to see whether the PGD treatment has been successful.

What are the chances of success with PGD?

As PGD involves using IVF, the success rate is relatively low compared to the chances of conceiving naturally. Of all patients who start PGD treatment, approximately one in five couples will have a baby. If the couple get as far as having embryos transferred, then approximately one in three couples will be successful.