

**Centre for Pre-implantation Genetic Diagnosis
Guy's & St Thomas' Hospital NHS Foundation Trust**

HLA PGD Patient referral form

*Please complete as fully as possible. Incomplete forms and missing data may result in a delay for your patients. **Please refer to the HFEA requirements on page 2 that will need to be met in order for a licence to be granted***

Referral criteria: The couple

- Patients must be: <37 yrs of age at referral
- Female BMI must be between 19 and 29
- Family history must support linkage analysis for single gene disorders
- Female hormone profile: AMH(anti mullerian hormone) ≥ 10 pmol/l
- FSH (follicle stimulating hormone) ≥ 10 IU/L
- Couple must be non smokers for at least 6 months
- Couples need to be aware that NHS funding is **not** available
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The child

- The patient must lack a well matched family/unrelated/cord blood donor
- The child's clinical condition is likely to remain stable for 3 years until a matched sibling donor is available

Referring clinician details	
Name: Designation: Address: Tel: Fax: Email:	
Centre undertaking the HSCT	
Name of clinician: Address: Tel: Fax: Email:	

Family details	
Female partner Name: DOB: NHS No:	
Male partner Name: DOB: NHS No:	
Child Name: DOB: NHS No:	
Address of couple:	
Referrers Hospital Number:	
Diagnosis (please include OMIM number)	
Name of Genetic Centre where family have been seen:	
Please complete the following sections as fully as possible. This detail is required for an HFEA licence application and missing data will delay application.	
1. Family history	
2. When diagnosis made in child	
3. Summary of child's health and current treatment	

4. Investigations and history of donor search		
5. Relevant obstetric/fertility history		
6. Details of other children		
Hormone profile results AMH: FSH:		
Female BMI		
Smoking status of both partners		
Essential information Please attach the following to this form when making a referral:		<ul style="list-style-type: none"> • Letter of support for HLA PGD to accompany the HFEA application • Copy of family tree • Relevant molecular or cytogenetic laboratory reports
Send form to: PGD Genetics Counsellors Clinical Genetics Department 7 th Floor, Borough Wing, Guy's Hospital, Great Maze Pond, London, SE1 9RT		If you would like to discuss a referral before sending please contact the following: Mrs Alison Lashwood or Prof Frances Flinter: Tel: 020 7188 1364 Email: jasbir.dhesi@nhs.net

HLA PGD/patientreferral/March 2017

HLAPGD/patient referral form/March 2017

HFEA Review of preimplantation tissue typing

Background

[Preimplantation tissue typing](#) is a technique which allows for the selection of embryos in order to bring about the birth of a child who can provide a matched tissue donation to an existing sibling. It is also sometimes called HLA tissue typing.

The first reported use of preimplantation tissue typing was in 2000 in the United States, when [preimplantation genetic diagnosis \(PGD\)](#) and preimplantation tissue typing was used to avoid the birth of a baby with an inherited condition and whose cord blood could also be used in a tissue donation to an existing sibling with the same condition.

Following detailed consideration by the HFEA's Ethics Committee the HFEA produced an interim policy on preimplantation tissue typing in November 2001. This policy approved, in principle, the licensing of PGD with tissue typing.

In 2004, after a period of public and professional discussion, the HFEA took the decision to review the interim policy.

Consultation process

The review was conducted by the Authority's Ethics and Law Committee (ELC), who researched the scientific and clinical developments, expert views on cord blood and bone marrow transplantation, legal developments, academic literature and public attitudes.

Research conducted in the course of the review included:

- consideration by the Scientific & Clinical Advances Group of the latest evidence relating to the risks associated with blastomere biopsy and implications for the resulting child
- expert psychosocial evidence and literature review concerning the experience of families and children in sibling cord blood and bone marrow donation
- expert evidence and literature review concerning current practice in cord blood and bone marrow donation for a range of conditions
- research into case law relating to consent and authorisation for procedures involving minors
- review of statements and opinions of UK, foreign and international ethics and advisory bodies relating to preimplantation tissue typing
- commissioned research into public opinion on issues related to embryo selection for tissue type and sibling cord blood and bone marrow donation.

The findings of the research indicated that preimplantation tissue typing was not necessarily an undesirable use of technology.

Consultation outcome

During its meeting in July 2004 The Authority considered the findings of the review on preimplantation tissue typing and agreed a revised policy.

The policy continued to allow for preimplantation tissue typing to be used only where there was an existing child affected by a serious or life-threatening condition and where all other possible treatments had been explored and discounted.

Applications would continue to be considered by the HFEA on a case-by-case basis.

The new guidance differed from the policy position established in November 2001 in the following principal respects:

- the new guidance recognised that preimplantation tissue typing may be acceptable in cases in which the embryo to be tested was not itself at risk from the condition affecting the existing child
- depending on the indications for the existing child, it may be acceptable to use preimplantation tissue typing with a view to using bone marrow from the resulting child
- detailed guidance relating to clinical decision making and patient information was included.

Further information

The HFEA is currently carrying out an evaluation of the licensing of HLA tissue typing applications and evaluation of the licensing of 'later onset' and 'lower penetrance' conditions.

As part of the evaluation the HFEA will gather evidence concerning how the HLA tissue typing policy has operated in licensing decisions made since 2001, and the impact of this on clinicians and patients.

<http://www.hfea.gov.uk/496.html#guidanceSection4365>