Paper Title: Born to Save? : The Ethics of Tissue Typing.

Author: Bellamy, Stephen
Institutional Affiliation: Ph.D student at the Centre for Religion and the Biosciences, University College, Chester, UK and Vicar of St James' church, Birkdale, Southport, UK.

This paper was prepared for "Science and Religion: Global Perspectives", June 4-8, 2005, in Philadelphia, PA, USA, a program of the Metanexus Institute (www.metanexus.net).

Abstract:

Technology has made it possible not only to achieve in vitro fertilisation but also to test IVF embryos for their tissue type. This enables the selection for implantation of an embryo with the matching tissue type to an existing seriously ill sibling. When the resulting child is born, cord blood can be collected and subsequently used as a source of potentially life-saving stem cells for its sick sibling. Tissue typing was first done in the USA in 1999 and compatible stem cells were successfully used to treat a girl suffering a serious and potentially fatal blood disorder.

A host of questions surround the practice of tissue typing. Is tissue typing compatible with a Christian view of what it means to be human or is it an unacceptably instrumental use of a human embryo or child? Does tissue typing constitute the first step down a 'slippery slope' to selecting embryos according to parental choice of desirable traits, in an unacceptable commodification of children? How significant is it that the request to tissue type is not driven by parental whim but by the serious medical condition in the ailing sibling? Should tissue typing be allowed for the purpose of providing donor cells to help not a sibling but another close relative, such as a parent? Is a future obligation placed on the tissue-matched child to continue to donate stem cells, tissue or even an organ to her ailing sibling? As preimplantation genetic diagnosis (PGD) is a relatively new technique, what safety risks are entailed to the embryo or future child through removing a single cell for testing or through misdiagnosis?

As with all use of embryos even for routine IVF, tissue typing is subject to strict control and regulation in the UK, with every case requiring a specific license, yet there is no such legal restraint on the performance of PGD or tissue typing in the USA. Which is the better position ethically in regard to the prevention of unacceptable uses of the embryo or to the monitoring of the safety of such novel procedures?

Some secular responses to questions about tissue typing will focus almost entirely on parental freedom and autonomy, yet this can be challenged as producing an ethic, driven by market forces, which could allow embryo selection and discard for almost any reason. Such a response ascribes no moral value to the embryo which is ever sufficient to overrule parental wishes.

Amongst the distinctive contributions of a Christian response will be compassion towards the sick coupled with a mandate to seek healing by legitimate means, the belief that limits do exist to the permissible selection and discarding of embryos, and that a child should be accepted as a gift of God rather than as a commodity that we specify.

Biography:
Stephen Bellamy is a parish priest in the Church of England, currently serving as Vicar of St James' church, Birkdale in Southport, UK. His undergraduate degree was in chemistry which he studied at Jesus College, Oxford. He trained for ordained ministry at St John's College, Nottingham and was one of the founder members of the Society of Ordained Scientists when it was inaugurated in 1987. In addition to his parochial ministry he is also a part-time Ph.D. student at University College, Chester, researching how a Christian theological anthropology can inform ethical decision-making about genetic interventions in humans.

Paper Text:

Born to Save? : The Ethics of Tissue Typing.

HLA (Human Leukocyte Antigen) tissue typing of IVF embryos facilitates the selection and implantation of an embryo which shares the HLA type of an existing seriously ill sibling. At the resulting child's birth, umbilical cord blood and placental blood can be collected and subsequently used as a source of potentially life-saving stem cells for its sick sibling.

There are widely divergent opinions about the acceptability of this new technology and while this account draws on Christian ethical principles, it makes no pretension to be the only possible Christian assessment.

History of selecting tissue-typed embryos as donors for siblings.

The first case of selecting a tissue-typed embryo was as a donor for Molly, the daughter of Jack and Lisa Nash, from Colorado who suffered from Fanconi's Anaemia. This inherited condition causes a major failure of bone marrow cell production. Children suffering from it have a life expectancy often reduced to around seven years and are frequently prone to die from leukaemia or other complications. As Fanconi's Anaemia is an autosomal recessive disease, there was a one in four chance that any child the couple had would suffer from it. So, although keen to have other children, they were understandably reticent because of the risk of having another seriously ill child. Yury Verlinsky and his team in Chicago[1] offered the Nashs IVF treatment combined with both preimplantation genetic diagnosis (PGD), to avoid having a child suffering the disease, and also tissue typing, so that the new child could be a donor for Molly. As a result, Adam Nash was born in August 2000 and his cord blood was collected and subsequently transfused into Molly, who is reported to be doing very well and may make a full recovery. The procedure was ethically significant as the first instance of the selection of a genetic trait, the matching HLA, which was not pertinent to the health of the child that the embryo would become[2] but vital to that of an existing sibling. Currently, neither PGD nor tissue typing is regulated in the USA.

In the UK, the Hashmi family were given permission by the Human Fertilisation and Embryology Authority (HFEA) in 2001 to try for a child who would

[1] Yury Verlinsky, Svetlana Rechitsky, William Schoolcraft, et al., 'Preimplantation Diagnosis for Fanconi Anemia Combined with HLA Matching', *Journal of the American Medical Association*, 285 (2001) 3130-3133.
[2] Thomas H. Murray and Eric Parens, 'Preimplantation Genetic Diagnosis: Beginning a Long Conversation', *Medical Ethics*, 9 (2002) 1-2, 8, (p. 2).

not only be free of the beta thalassemia suffered by their son Zain but would also be a tissue match and potential donor for him. Amongst the stringent conditions the HFEA imposed at that time were that: the condition of the affected child should be of a sufficient seriousness to justify the use of PGD, the techniques should not be available where the intended recipient is a parent, the intention should be to take only cord blood for purposes of the treatment and not other tissues or organs, and that the embryos conceived in the course of the treatment should themselves be at risk from the condition by which the existing child is affected. This latter stipulation meant that another British couple, the Whitakers, seeking a tissue matched child to aid their son Charlie were forced to seek help from Verlinsky's team in Chicago. This was because the Diamond Blackfan Anaemia suffered by Charlie was the result of a sporadic mutation so that any embryos conceived as possible tissue donors would not have been at risk of suffering this disease. They successfully conceived a tissue-matched child who was born in June 2003. A life-saving transfusion for Charlie was attempted during 2004 and the initial indications are encouraging. Subsequently other families in the UK[3], Australia[4] and the USA[5] have sought and in some cases conceived a tissue-matched child.

In July 2004, the HFEA announced that it had now decided to extend permission to tissue type to cases, like that of the Whitakers, where the embryo to be selected is not itself at risk of possessing the disease in question. The HFEA's reversal of its previous decision came after review of the medical, psychological and emotional implications for children and their families and after three more years of experience of embryo biopsy which reinforced opinions that the process is sufficiently safe. The HFEA did however reiterate that tissue typing would only be contemplated as a 'last resort' when all other avenues of treatment or of supply of donor cells had been exhausted[6].

Tissue typing and the moral status of the IVF embryo.

In PGD a single cell is taken from an IVF embryo when it consists of about eight cells, three days after fertilisation. This does not prevent the subsequent normal development of the embryo. Usually the cell is removed in order to check that the embryo being tested will not suffer from a known familial disease. Tissue typing is the particular analysis of this biopsied cell to discover its HLA tissue type. This genetic trait, coded for on part of chromosome 6, specifies aspects of the immune system and is a feature which, statistically, will be shared by one in four of the offspring of a couple. An embryo of the same tissue type as an ailing sibling can be implanted and grow into a child whose cells may be transfused to the sick sibling without rejection by the sibling's immune system.

---

[3] BBC Television,'Designer Baby Rules May Change', *BBC 1 News,* 17 July 2004, <http://news.bbc.co.uk/go/pr/fr/-/1/hi/health/3902407.stm> [accessed 17 July 2004]

[4] Zoe Taylor, 'Baby created to cure brother', *The Australian*, 8 March 2004, <http://www.theaustralian.news.com.au/printpage/0,5942,8898613,00.html> [accessed 15 March 2004]

[5] Yury Verlinsky, Svetlana Rechitsky, Tatyana Sharapova et al., 'Preimplantation HLA Testing', *Journal of the American Medical Association*, 292 (2004) 2079-2085.

[6] HFEA Press Release,' HFEA Agrees to Extend Policy on Tissue Typing', 21 July 2004 <http://www.hfea.gov.uk/PressOffice/Archive/1090427358> [accessed 27 July 2004] and HFEA Report, 'Preimplantation Tissue Typing', para. 23, p. 7. <http://www.hfea.gov.uk/AboutHFEA/HFEAPolicy/Preimplantationtissuetyping > [accessed 27 July 2004]

It is significant that whether or not tissue typing is considered a dilemma depends entirely on one's view of the moral status of the embryo. If it is argued that embryos are to be treated as having an equal moral status to that of postnatal human beings, then tissue typing will be adjudged an illicit procedure because it inevitably involves the destruction of unselected embryos, as does routine IVF. Some Christians and others would conscientiously take this view and reject any selection of embryos. It means that this absolute respect for the embryo takes precedence over any considerations for the welfare of any existing child. This is not an approach I feel it necessary to adopt from a consideration of either scripture or science. Secondly, if the IVF embryo is regarded as having no moral status at all, or that parental autonomy over the use of embryos will consistently overrule all other considerations, then there will be no hesitation in concluding that tissue typing is acceptable. Such consideration of the human embryo as completely devoid of worth is, I believe, untenable from a Christian perspective.

Tissue typing provides a dilemma only for those, like me, who believe that the IVF embryo is to be afforded some moral weight even if it is not of the same moral status as a living person. This implies a degree of respect for embryos, so that they can only be used in limited ways. In Christian terms we might say that the IVF embryo is in the process of development in which it may subsequently, after further human intervention, become a person made in the image of God. It is from the standpoint of this position on the status of the IVF embryo that the following discussion will be engaged.

In addition to this view of the embryo, a Christian approach to tissue typing should be undertaken cognisant that we did not create and design ourselves, that we may lack the wisdom always to make the right decisions and that we face great responsibilities in making selection decisions about IVF embryos. One consequence of this will be that we face the necessity of going back and tightening our regulations if our decisions are shown, after further monitoring, to have been wrong e.g. if we find that a risk taken has been too great.

While adequate weight must be given to the strong Christian mandate to heal, it should also be acknowledged that not all possible methods of healing will be acceptable. The dilemma therefore presents itself in terms of whether the techniques of PGD and tissue typing provide an ethically acceptable method of attempting to heal an existing seriously ill sibling.

Should tissue typing be allowed?

A response to this question can be sought by examining two significant areas of ethical debate concerning tissue typing. These are:

(1) selection and donation issues, which could provide possible intrinsic reasons for eschewing tissue typing such as its being an unacceptable instrumentalisation or commodification of the embryos or donor children concerned, or if it would create serious problems for the donor child perhaps of a psychological nature,

(2) safety issues, which could provide consequential reasons not to proceed if tissue typing is not sufficiently safe for the embryos or donor children involved. Thus the safety of the PGD/tissue typing process and of possible misdiagnosis is considered.

(1) Selection and donation issues.

(i) Does tissue typing entail the unacceptable instrumentalisation of embryos?

Kant's dictum that we should never treat a person simply as a means, but always at the same time as an end[7] can be used an indicator for the assessment of unacceptable instrumentality. In theological terms, this prohibition can be seen as a negative implication of Jesus' charge in Matthew 22:39 that we should treat our neighbour with agape love[8]. We need to consider whether the actual process of selecting IVF embryos on the basis of tissue type entails unacceptable instrumentality. If it does, this constitutes an ethical reason to prohibit tissue typing because the assertion that the child will be loved when it is born does not overrule the wrong done if the embryo has initially been used in an unacceptably instrumental way[9].

A totally unacceptable instrumentality would indeed be evidenced by the abortion of a tissue-matched foetus to obtain stem cells. Such an action would be illegal in the UK and the USA though some procreative liberty protagonists argue in its favour[10]. We concur with Verlinsky et al. who reject prenatal diagnosis to check for HLA type if the motive would be termination because abortion 'could not be justified for the reasons of HLA incompatibility'[11]. Even so, such abortions have taken place in the past when parents have tried naturally for a tissue-matched child[12]. In the UK, the law also prohibits the dismemberment of a tissue-matched IVF embryo for its stem cells though the identical process is now permissible for other medical purposes when an embryo has been cloned from a patient.

The status of IVF embryos and to a greater extent foetuses, as protectable beings, derives both from our relationship to them, because we are responsible to God to live as those made in God's image, and also from their teleology as those who can potentially become human beings made in God's image. In contrast, their purpose is entirely denied by embryo dismemberment or foetal termination for donor cells and our stewardship is thereby abrogated.

It should be noted that a degree of objectification is inherent in the use of IVF and its concomitant selection of embryos. This is because IVF allows us to intervene between conception and implantation and the IVF embryos lie open to our gaze and require us to make a definite decision about their future. The question is whether it is permissible to discard 'healthy' embryos on the basis of their not having the right tissue type to be a donor to a sibling. Whereas all previous reasons to select and discard embryos contribute either to bringing a child to birth, in routine IVF to overcome fertility problems or, in the use of PGD, to avoid serious disease, the selection done in tissue typing rejects healthy embryos because they cannot be donors for their ailing sibling. Tissue typing presents the first instance of selecting for or

---

[7] I. Kant, *The Groundwork of the Metaphysics of Morals*, (New York: Harper and Row, 1964).
[8] John Bryant and John Searle, *Life in Our Hands: A Christian Perspective on Genetics and Cloning*, (Leicester: Inter-Varsity Press, 2004) p.148.
[9] Roger Brownsword, 'Reproductive Opportunities and Regulatory Challenges', *Modern Law Review*, (2004) 304-321 (p. 314).
[10] John A. Robertson, Jeffrey P. Kahn and John E. Wagner, 'Conception to Obtain Hematopoietic Stem Cells', *Hastings Center Report*, 32 (2002) 34-40 (p.37-38).
[11] Verlinsky, et al., 'Preimplantation HLA Testing', p.2079.
[12] Susan M. Wolf, Jeffrey P. Kahn and John E. Wagner, 'Using Preimplantation Genetic Diagnosis to Create a Stem Cell Donor: Issues, Guidelines and Limits', *Journal of Law, Medicine and Ethics*, 31 (2003) 327-339 (p. 328).

against embryos solely on the basis of their possessing or lacking a genetic trait, HLA type, which is irrelevant to their own welfare, having no immediate bearing on their suffering a serious disease. Allowing tissue typing to proceed by bringing to birth a child to be received and loved by its family preserves the teleology of embryos as potential persons to the same extent as it is preserved by allowing selective implantation of embryos in the usual use of IVF or in their selection using PGD.

Such embryo selection, whether in PGD or in normal IVF, is ruled out by those who argue that the IVF embryo already has the same status as that of a postnatal child. There is also the strange irony that, over the issue of tissue typing, organisations which style themselves as 'pro-life' in terms of protection of the embryo are arguing against saving the life of a presently existing child. A spokesman for the Society for the Protection of the Unborn Child has been quoted as making the remarkable statement that ' just because a child's life is at stake does not mean that you discard all ethics'[13] which implies that 'ethics' applies only to saving embryos but not existing children.

Allowing the IVF embryo its proper degree of respect entails not creating and disposing of embryos for trivial reasons. Performing IVF for the treatment of infertility can be argued to be a non-trivial use of embryos even if not all the healthy embryos are implanted. In PGD, the avoidance of serious disease legitimises discarding embryos, including perhaps some healthy embryos where there is a surplus. So also in tissue typing it is the intention to heal disease, albeit in a sibling, that provides the non-trivial motive for discarding embryos. As Roger Brownsword puts it, as he questions making a distinction between PGD and tissue typing, why 'is the informed choice of parents for prevention regarded as a more compelling reason than their informed choice for cure?[14]'

Thus, I suggest that a commitment to Christian compassion for the sick allows an exceptional use of the selection of embryos in the case of tissue typing to save an ailing sibling. The exceptional nature of the case is preserved as it is argued that it should be the one and only use of the selection of a genetic trait unrelated to disease and which is not immediately relevant to the future health of the child produced. It should be noted that this exception could only be upheld in practice if supported by explicit legislation setting this limit.

Having shown that the actual process of embryo selection need not be disqualified as unacceptable instrumentality, it is now necessary to examine whether tissue typing instrumentalises the donor child.

(ii) Does tissue typing entail the unacceptable instrumentalisation of children?

The Ayala family took a risk in 1990. The husband's vasectomy was reversed and they conceived a child naturally with in the hope s/he would be a tissue match for a seriously ill teenage sibling. They were successful though there was only a one in four chance of having a tissue match. The family seemed surprised by some of the questions ethicists raised about their loving the new child, assuring everyone that the baby would be much loved for herself and not because of what she could donate to her sister[15]. Here we are considering the use of technology to ensure that the embryo

---

[13] Bryant and Searle, p. 126.
[14] Brownsword, p. 317.
[15] John A. Robertson, *Children of Choice: Freedom and the New Reproductive Technologies,* (Princeton: Princeton University Press, 1994) p.214-215.

is a certain tissue match without recourse to the 'genetic lottery' of the one in four chance of successfully conceiving a tissue matched child.

The fact that children are born from a wide range of parental motives cannot be ignored. These imply varying degrees of instrumentality and some appear more acceptable than others. Such motives include having a child who will: run the family business, keep the line going, look after me in my old age, be a playmate for an existing sibling, hold our marriage together, be someone to share our love with, enable us to enjoy being mum and dad, be the son (or daughter) we want to have. Bringing a child into the world to be loved for herself and also to be a donor for a sibling may well seem as good a motive as some, such as conception 'by accident', and better than many, such as being the result of a casual sexual encounter. However, the fact that there are bad reasons for having children would not legitimise sanctioning another bad reason[16]. Rather, as the theologian Ted Peters put it 'when bringing children into the world…. all parents have mixed motives all of the time[17]'.

With a degree of instrumentality in all child bearing, what we need to ensure is that tissue typing does not lead to *unacceptable* instrumentality. An unacceptably instrumental use of the donor child would be if she were rejected after birth and put up for adoption after the donation of the stem cells. Astonishingly, John Robertson[18] and Norman Fost[19] do not think even this would be unacceptable instrumentality as the child could have a happy life with adoptive parents. Their attitude incidentally confirms that unrestrained procreative liberty arguments are ethically flawed in being unable to offer any counter to parental wish even in order to prevent what would be considered by most as a flagrant abuse of children. Their stance is cogently refuted by G. Pennings et al. who point out that such a rejection 'shows beyond doubt that the sole motive for having the child was its tissue' and that actual harm is done to the child by its parents' 'blatant demonstration of disrespect'[20] which, in Christian terms, is the dereliction of parental stewardship with its gracious welcome to the child.

It is therefore of prime significance in refuting the charge of unacceptable instrumentality towards children that the parents do want the donor child for herself as well as for her potentially life-saving donation and intend, as far as can reasonably be ascertained, to receive the child with unconditional love. Karen Sermon et al. recommend careful counselling by psychologists to 'ascertain the real motivations of the prospective parents'[21] in this respect. Pennings et al. concur and suggest that a psychologist trained in fertility counselling could notice if there were any untoward contradictions in the parents' attitude to the new child[22].

Interviews with the two families seeking tissue typing in the UK, the Hashmis[23] and the Whitakers[24], have indicated the depth of love these families have for their children. This is confirmed by their being willing to undergo the arduous

---

[16] HFEA Ethics Committee, 'Ethical Issues', para.3.5, p. 9-10.
[17] Ted Peters, Personal Communication, 26 October 2003.
[18] Robertson, *Children of Choice*, p.217.
[19] Norman C. Fost, 'Conception for Donation', *Journal of the American Medical Association*, 291 (2004) 2125-2126 (p.2126).
[20] G. Pennings, R. Schots and I. Liebaers,' Ethical Considerations on Preimplantation Genetic Diagnosis for HLA Typing to Match a Future Child as a Donor of Haematopoietic Stem Cells to a Sibling', *Human Reproduction*, 17 (2002) 534-538 (p.536).
[21] Karen Sermon, Andre Van Steirteghem, Inge Liebaers, 'Preimplantation Genetic Diagnosis – Review', *The Lancet*, 363 (2004) 1633-1641 (p.1636).
[22] Pennings, et al., 'Ethical Considerations', p.538.
[23] Channel 4 Television, 'Conversations with the Archbishop', 26 September 2003, Channel 4.
[24] BBC Television**, '**A Baby to Save our Son', 9 December 2003, BBC1.

processes tissue typing requires for the sake of their existing unwell child. Several commentators acknowledge that it is highly unlikely that they would subsequently refuse to extend that same love to any further child of theirs[25]. The HFEA Ethics Committee even suggested that 'the element of utility in the parents' decision to conceive clearly does not rule out their benevolent intention to love and care for the child'[26].

Another instance of unacceptable instrumentality would be if the child were forced to undergo painful and invasive procedures against its will for the sake of another. Addressing this concern in the context of the USA, Susan Wolf et al. recommend protections for the donor including:

(a) insisting that there should be psychological evaluation of the parents, and, when of a suitable age, the child also before an invasive harvesting of stem cells. This ensures that the parents are not imposing psychological harm on the child or exploiting her and also to verifies that the child receives adequate support and does not object to the procedure,

(b) limiting to no more than two, and possibly only one, the number of harvesting procedures before the child can make a decision for herself, with no harvesting taking place from neonates, and

(c) appointing an independent physician to safeguard the interests of the donor child[27].

In the UK, the HFEA's initial stipulation that the intention should be to take only cord blood from the donor child[28] has been modified so that the question of subsequent bone marrow donations is decided by the doctors and patients concerned[29]. The HFEA does not have the power to impose a condition on the licence to tissue type that would prevent attempts to obtain bone marrow in the future if a cord blood donation failed, but it was satisfied that the child's protection in UK law would prevent any solid organ donation[30]. However, we consider that the establishment of a protocol in line with the recommendations of Wolf et al. would help prevent any ongoing invasive procedures being forced upon the child.

Thus we conclude that tissue typing of itself does not instrumentalise a child or prevent him being welcomed with agape love and cared for as an end in himself. Nevertheless, a Christian view of parental stewardship cannot endorse S. Sheldon and S. Wilkinson's assertion that ' there is nothing objectionable about creating a baby as a "means to an end" provided that it is also viewed and treated as a human being'[31]. Receiving a child in love so that she is 'viewed and treated as a human being' remains only a necessary but not a sufficient feature of our agreeing to the acceptability of tissue typing. It is not enough on its own because, without further qualification,

---

[25] Pennings, et al., 'Ethical Considerations', p.536; Robertson, 'Extending Preimplantation Genetic Diagnosis', p.468; HFEA Ethics Committee, 'Ethical Issues', p.9, para.3.3.
[26] HFEA Ethics Committee, 'Ethical Issues', p.9, para.3.4.
[27] Wolf et al., Using Preimplantation Genetic Diagnosis..', p.333-335.
[28] HFEA Press Release, 'HFEA confirms..', 1 August 2002.
[29] HFEA, Minutes of Meeting on 21 July 2004, p.3, <http://www.hfea.gov.uk/AboutHFEA/AuthorityMinutes/2004/July2004> [accessed 27 July 2004]
[30] HFEA Report, 'Preimplantation Tissue Typing', p.7, para. 26. In addition, Pennings, et al., ('Ethical Considerations', p.537) and HFEA Ethics Committee ('Ethical Issues', p.10, para.3.8) also restrict future expectations on the donor to possible bone marrow harvest.
[31] S. Sheldon and S. Wilkinson, 'Should selecting saviour siblings be banned?', *Journal of Medical Ethics*,30 (2004) 533-537 (p.534). Similar comments are made in Robert J. Boyle and Julian Savulescu, 'Ethics of Using Preimplantation Genetic Diagnosis to Select a Stem Cell Donor for an Existing Person', *British Medical Journal*, 323 (2001) 1240-1243, (p. 1241).

receiving with love the child that is born would not circumvent the unacceptable selection or design of all kinds of traits in the embryo to be implanted. For an intervention to be acceptable the child must not only be received with love but also the intervention must not be such as to distort the relationship of love between parents and children[32]. Within this relationship, a Christian approach to parental stewardship views the child as primarily belonging to God and also to itself and thus not being the 'possession' of the parents in any ultimate sense[33], but rather a gift on loan from God[34]. This prompts the question about whether tissue typing means the child to be is treated as a commodity rather than being accepted as a gift from God.

(iii) Does tissue typing entail the commodification of children?

Commodification of children can be said to occur when sought-after characteristics in the embryo are chosen in order to fulfil parental whims and personal desires about the constitution of future children. Such selection not only distorts the relationship of love and acceptance of the child-to-be for themselves, it also damages the humanity of the parents through their regarding their prospective child as a project of their own design rather than as the stranger they welcome as a gift of God.

However, the request for tissue typing is not of this kind. The trait, HLA type, is not of the parents' free choosing but the specific and only one which must be chosen if a compatible donor sibling is to be born and a child's life is to be saved. This is not a self indulgent or evil motive, nor a free and capricious engineering of traits or a frivolous misuse of embryos. Rather it is an urgent request for a highly specific selection which the parents did not anticipate or desire. The families involved would far prefer not be in this position of needing to choose an embryo; they are being driven by a compassionate response to medical necessity and not by personal aspiration and are entirely constrained in the kind of intervention being sought. Their request is compatible with the strong presumption in favour of seeking healing, albeit by legitimate means, that Christian theology mandates.

I suggest that the parents' *reactive* response in seeking tissue typing is of a different character from any *proactive* seeking to fashion the 'child of my choice' and provides the morally significant distinction with which to fence off the slippery slope to so-called 'designer babies'. We should not wish to arrive at the bottom of that slope where children are treated as commodities, as our objects or projects to be selected for the genetic traits we would prefer in our offspring. Tissue typing is clearly not that and it remains possible, at least in the UK, to legislate so that tissue typing remains the one and only allowable instance of the selection of a genetic trait which is itself incidental to the future health of the embryo being selected. In the USA, where even sex selection for reasons of parental preference is not illegal, such regulation may be more difficult. Thus a case can be made that tissue typing does not lead to the unacceptable commodification of children.

The commodification debate raises the more general question of the limits to parental choice in the use of embryos. With options about the use of embryos being delivered into the most consumerist society in history, the UK is fortunate to have

---

[32] Neil G. Messer, 'Human Genetics and the Image of the Triune God', *Science and Christian Belief*, 13 (2001), 99-111 (p.105).

[33] Sondra Wheeler, 'Parental Liberty and the Right of Access to Germ-Line Intervention: A Theological Appraisal of Parental Power', in *Designing our Descendants*, ed. by Audrey R. Chapman and Mark S. Frankel, (Baltimore: John Hopkins University Press, 2003) pp. 238-251 (p.244).

[34] Brent Waters, *Reproductive Technology: Towards a Theology of Procreative Stewardship*, (London: Darton, Longman and Todd, 2001), p.3.

regulations policed by the HFEA and a principle of 'constrained parental decision making'[35]. While space precludes discussion of the dangers of the unrestrained parental autonomy advocated by some[36], we should note that if parental rights over embryos were allowed invariably to take precedence over parental responsibilities to future children, we would have become market led (for parents are the market) and would allow embryos no significance compared with parental desire.

(iv) Is tissue typing likely to cause psychological harm to the donor child?
It could be suggested that selecting a tissue matched embryo will cause psychological problems later for the resulting child about her only being wanted because of her tissue type and feeling used by her parents or older sibling[37]. However, it could also be that a donor child will feel proud to have contributed in such an important way to the well being of a sibling[38]. Robertson et al. suggests that donor and donee would have a special bond with each other whether or not the transplant of cells succeeded. If it did the donor has made a huge contribution to household welfare, if not the parents are unlikely to blame the donor and will still have this child to love[39].

Issues relating to the psychological effect of the actual tissue donation when considering the restriction and monitoring of subsequent bone marrow, as opposed to cord blood, donations have already been discussed. There is some evidence for psychosocial problems suffered by sibling donors of bone marrow, who have shown more anxiety and lower self-esteem than non-donor siblings[40]. These problems are lessened in cord blood donation[41] and greater in bone marrow donation because the psychological effect on the donor is due to the conscious experience that the donor has of the donation. In contrast, the donor sibling has no awareness of donating cord blood and does not understand what has happened until much later when any psychosocial harm will have become diluted by time. Also the child will probably later agree with the parental decision made for him to be a donor, as he will probably have come to value his relationship with his sibling[42].

Sheldon and Wilkinson suggest that it is unlikely that a tissue typed donor child 'would be *less* happy than another, randomly selected sibling… who was unable to act as a tissue donor'[43]. John Polkinghorne comments that care would have to be taken in informing the donor child in due course because 'properly handled, one would hope that the child would see himself as having given a great gift to the sibling'[44].

---

[35] HFEA Ethics Committee, 'Ethical Issues in the Creation and Selection of Preimplantation Embryos to Produce Tissue Donors', 22 November 2001, para.3.11.
[36] For example: R.J. Boyle and J. Savulescu, 'Ethics of using preimplantation genetic diagnosis to select a stem cell donor for an existing person', *British Medical Journal* 323 (2001) 1240-1243; J. Harris, 'Rights and Reproductive Choice', in *The Future of Human Reproduction,* ed. by J. Harris and S. Holm, (Oxford: Clarendon Press, 2000); J.A. Robertson, *Children of Choice*, (Princeton: Princeton University Press, 1994);
[37] Louise M. Terry, 'The Child that Might be Born…', *Hastings Center Report*, 32 (2002) 11-12 (p.11).
[38] Pennings, et al., 'Ethical Considerations', p.537-538; see also Sheldon and Wilkinson, p.536.
[39] Robertson, et al., 'Conception to Obtain Hematopoietic Stem Cells', p.36.
[40] The Lancet Editorial, 'Preimplantation Donor Selection', *The Lancet*, 358 (2001) 1195,
[41] Giuseppe Roberto Burgio and Franco Locatelli, 'Ethics of Creating Programmed Stem-cell Donors', *The Lancet*, 356 (2000) 1869.
[42] Pennings, et al., 'Ethical Considerations', p.537-538.
[43] Sheldon and Wilkinson, p.536.
[44] John Polkinghorne, Personal Communication, 16 October 2003.

Without empirical evidence, possible psychological harms remain too speculative to prohibit tissue typing[45]. But the HFEA's recommendations about counselling and follow up studies of children and their families should be implemented as this will provide helpful monitoring for any of these potential problems[46]. Ultimately much depends on how the situation is dealt with within the family. Certainly with love, care and the grace of God, there need be no major problem any more than there need be in the explanation of other less usual family circumstances such as adoption.

(v) Can tissue typing be allowed to assist other close relatives e.g. a parent?

In considering whether tissue typing should be allowed for the purpose of providing donor cells to help not a sibling, but perhaps a sick parent or other close relation, it should be noted that in such cases it is a partial HLA match that would be sought as it would not be possible to achieve a complete HLA-match.

Anver Kuliev has commented that any embryo inheriting its HLA coding on both copies of its chromosome 6 from only one parent would be not only rare but also likely to suffer adverse effects. He suggests that the necessary partial tissue match to aid a non-sibling would be much more practically achieved by searching existing donor registers than by selecting a tissue-matched embryo[47]. Using the latter method in these circumstances would go beyond regarding tissue typing as a last resort. Moreover, part of the evidence that parents using tissue typing to help an ailing sibling are not guilty of unacceptable instrumentality or commodification comes from their demonstration of love for their children revealed by their strenuous efforts to save the ailing sibling. Such evidence would be lacking if the embryo selected as a donor for a non-sibling were to be a first child. Furthermore, the case of seeking a donor to help a parent introduces self-interest as a major factor in selecting the child.

The HFEA originally ruled out tissue typing in order to help a parent[48] on the advice of its Ethics Committee[49]. It is now sounding more equivocal, suggesting that the matter is more ethically problematic than in the case of tissue typing to save a sibling and needs further consideration[50]. The principles whereby embryo selection is permissible within a narrowly defined range of medical purposes which do not distort the child-parent relationship nor involve unacceptable instrumentality or commodification necessitate holding the HFEA to its assertion that tissue typing really is a 'last resort' procedure[51].

Having dealt with these possible intrinsic objections to tissue typing we must now consider whether tissue typing is sufficiently safe to be performed.

(2) Safety issues.

Turning to questions about the safety of tissue typing, it is necessary to assess the degree of risk involved in two particular areas: (i) biopsy damage to the embryo and tissue typing and (ii) the misdiagnosis of disease or of tissue type.

---

[45] Louise M. Terry, 'The Child that Might be Born…', *Hastings Center Report*, 32 (2002) 11-12 (p.11).
[46] HFEA Report, 'Preimplantation Tissue Typing', para. 17, p.5.
[47] A. Kuliev, personal communication, 24 November, 2004.
[48] HFEA Press Release, 'HFEA confirms..', 1 August 2002.
[49] HFEA Ethics Committee, 'Ethical Issues..', para.3.15.
[50] HFEA, Minutes of Meeting on 21 July 2004, p.5.
[51] HFEA Report, 'Preimplantation Tissue Typing', para. 23, p.7.

(i) Biopsy damage to the embryo.

The HFEA suggest that embryo biopsy causes a risk of damage of under 5% and that such damage usually renders the embryo non-viable[52]. It may be that damage other than that caused by lack of care in aspirating the cell will always be difficult to assess because of the high rate of over 65%[53] for abnormalities present in all cohorts of IVF embryos.

The evidence on outcomes of pregnancy is more readily available. E. Kanavakis et al.[54] acknowledge the major concern for the safety of children born after PGD but report that early analysis after 250 births following PGD suggests that ' the procedure has no adverse effects on early development'. The European Society of Human Reproduction and Embryology (ESHRE) Task Force[55] similarly conclude that PGD babies do not seem to be exposed to greater risk of neonatal problems or malformations. Similarly Verlinsky et al.'s analysis of 12 years multi-centre PGD experience assesses congenital malformation rate at birth as 'not different from population prevalence'[56]. Other surveys of obstetric outcome corroborate the above observations[57]. Suzi Leather, chair of the HFEA, comments that while 'PGD damages and destroys some embryos', yet ' it seems safe for those which develop into foetuses and subsequently into children'[58]. This seems a fair conclusion based on the available evidence noted above.

I am indebted to Dr. Caroline Berry for emphasising the urgent need for a full long-term follow-up study of a large cohort of children born after PGD in order to provide a proper assessment of the safety risks posed by PGD[59]. The HFEA have commented that in PGD 'we cannot absolutely rule out the small chance of some long-term adverse effects for offspring'[60] and several practitioners and ethicists including Flinter[61], HFEA/HGC[62], Holm[63], and Winston and Hardy[64] concur noting that although short-term evidence suggests no ill effects from embryo biopsy, its

---

[52] HFEA Report : Preimplantation Tissue Typing, para. 13, p.4.
[53] E. Kanavakis and J. Traeger-Synodonis., 'Preimplantation Genetic Diagnosis in Clinical Practice', *Journal of Medical Genetics*, 39 (2002) 6-11 (p.9).
[54] Kanavakis and Traeger-Synodonis, p.9.
[55] ESHRE Task Force 5, (F. Shenfield, G. Pennings, P. Devroey, et al.), 'Preimplantation Genetic Diagnosis', *Human Reproduction*, 18 (2003) 649-651, (p. 650).
[56] Yury Verlinsky, Jacques Cohen, Santiago Munne, et al., 'Over a Decade of Experience with Preimplantation Genetic Diagnosis: A Multicenter Report', *Fertility and Sterility*, 82 (2004) 292-294 (p.294).
[57] C. Strom, S. Strom, E. Levine, et al.,'Obstetric Outcomes in 102 Pregnancies after Preimplantation Genetic Diagnosis', *American Journal of Obstetrics and Gynecology*, 182 (2000) 1629-1632 (p.1629); European Society of Human Reproduction and Embryology (ESHRE), Preimplantation Genetic Diagnosis Consortium Data Collection III (May 2001), *Human Reproduction*, 17 (2002) 233-246 (p.237); N. Ouhibi, P.E. Patton, K.A. Burry, et al., 'Preimplantation Genetic Diagnosis: Does Embryo Biopsy for PGD Compromise Clinical Outcome?', *Fertility and Sterility*, 79 (2003) 23.
[58] Suzi Leather, 'Saviour Siblings : Is it Right to Create a Tissue-typed Baby?', Progress Educational Trust, <http://www.progress.org.uk/events/PastEventsSSLLeather.html> [accessed 9 March 2004]
[59] Caroline Berry, Personal Communication, 31 December 2003.
[60] HFEA, Sex Selection, para. 121, p. 31.
[61] Frances Flinter, 'Preimplantation Genetic Diagnosis Needs to be Tightly Regulated', *British Medical Journal*, 322 (2001) 1008-1009, (p.1009).
[62] HFEA/HGC, Outcome, p. 6, para 29.
[63] Soren Holm, 'Ethical Issues in Pre-implantation Diagnosis', in *The Future of Human Reproduction*, ed. by J. Harris and S. Holm, (Oxford: Clarendon Press, 2000), pp. 176-190, (p.177).
[64] Winston and Hardy, p. S17.

longer-term effects on child development are not known and follow-up studies will be important[65].

We therefore conclude that PGD biopsy is sufficiently safe for it to proceed in line with the HFEA's latest announcement on tissue typing[66], with the proviso that long-term studies are done to assess any affect on children born after PGD and after tissue typing.

(ii) Misdiagnosis errors.

The second part of the safety consideration in PGD and tissue typing is the danger of misdiagnosis i.e. of misdiagnosing an affected embryo as 'healthy' and acceptable for implantation and also of misdiagnosing a non tissue-matched embryo as a suitable stem cell donor. Robert Winston and Kate Hardy[67] comment that, in PGD, misdiagnosis appears to be a greater risk than biopsy damage. Figures for misdiagnosis rates are becoming more available but they vary considerably and reports are often anecdotal[68].

There are several sources of error associated with cell biopsy and amplification of DNA from single cells. These include: contamination in the laboratory process with sperm or with maternal cumulus cells, this is reduced by the use of intracytoplasmic sperm injection (ICSI); allele dropout, where only one of two alleles present is successfully amplified; the mosaicism[69] that many human embryos suffer resulting in the cell that is analysed not being representative of the whole embryonic genome[70] and failure of the polymerase chain reaction. The HFEA's patient information on PGD[71] quotes a risk of misdiagnosis at around 5%. Joanne Traeger-Synodinos et al.[72] report PGD misdiagnosis of 7.1% over 3 years work in PGD to avoid two forms of thalassemia. C.M. Lewis et al.[73] describe a model for controlling misdiagnosis errors which encompasses extrinsic sources of error through laboratory processes and intrinsic errors due to abnormalities in the cell nucleus or chromosomes. When a linked marker was analysed as well as the disease alleles, the probability of error in the genotype of an affected embryo was drastically reduced from 5.8% to 0.44% for a recessive disease and from 10.9% to 0.1% for a dominant disease.[74] Lewis et al. note that although genotyping two cells increases the proportion of unaffected embryos that will be transferred, the removal of two cells may adversely affect the embryonic implantation rate.[75] Refining the PGD technique for recessive

---

[65] The ESHRE PGD Consortium plans to seek funding from the EU for such a follow up project, see Sermon et al., 'The future plans of the ESHRE PGD Consortium'.
[66] HFEA Press Release, 'Extend Policy', 21 July 2004.
[67] Winston and Hardy, p. S17.
[68] Sermon et al., PGD Review, *The Lancet*, 363 (2004) p.1638.
[69] Dagan Wells and Joy D.A. Delhanty, 'Comprehensive Chromosomal Analysis of Human Preimplantation Embryos Using Whole Genome Amplification and Single Cell Comparative Genomic Hybridization' *Molecular Human Reproduction*, 6 (2000) 1055-1062 (p.1055).
[70] Winston and Hardy, p. S17.
[71] HFEA Patient Information Leaflet, 'Preimplantation Genetic Diagnosis for Single-Gene Disorders and HLA (Tissue) Typing' February 2002, p.3.
[72] Joanne Traeger-Synodonis, Christina Vrettou, Giles Palmer et al., 'An Evaluation of PGD in Clinical Genetic Services Through 3 Years Application for Prevention B-thalassaemia Major and Sickle Cell Thalassaemia', *Molecular Human Reproduction*, 9 (2003) 301-307.
[73] C.M. Lewis, T. Pinel, J.C. Whittaker and A.H. Handyside, 'Controlling Misdiagnosis Errors in Preimplantation Genetic Diagnosis: A Comprehensive Model Encompassing Extrinsic and Intrinsic Sources of Error', *Human Reproduction*, 16 (2001) 43-50.
[74] Lewis et al., p.46.
[75] Lewis et al., p.49.

diseases to obtain two genotypes – either based on marker and disease genotypes in a single cell or from disease genotypes in two cells – greatly reduces misdiagnosis rates, as does taking both disease and marker genotypes from two cells in the case of dominant diseases. The latest version of the most comprehensive analysis of PGD by ESHRE[76] reports rates of misdiagnosis as 1.8% on average.

Winston and Hardy's contention that misdiagnosis is a greater hazard in PGD than biopsy damage appears to be confirmed by the available evidence but the misdiagnosis risk is still within acceptable limits and is diminishing with experience. Interestingly however, there are no reports as yet of misdiagnosis of HLA type. Van de Velde et al.[77] and Verlinsky et al. similarly note 100% success in determining tissue type[78]. This suggests that tissue typing without PGD for disease, though in its early days, can be sufficiently safe from misdiagnosis and that PGD with tissue typing need be no more hazardous in terms of misdiagnosis than PGD alone.

Having now answered both the possible intrinsic objections to tissue typing concerned with commodification, instrumentality and psychological effect and also the consequentialist concerns regarding safety, some comments are necessary on the present state of legislation concerning tissue typing.

Regulation of Tissue Typing.

Though the main discussion here will be of the state of British law regarding tissue typing, it should be noted that tissue typing has been allowed in Victoria, Australia[79] and that, significantly, neither Japan[80] nor the USA[81] yet have regulation of PGD or tissue typing. The recent report on PGD by the Genetics and Public Policy Center (GPPC)[82]is to be welcome and, hopefully, it will contribute to the growing awareness in the USA that without regulation there can be no assurance of ethical practice in the treatment of embryos or even in the avoidance of exploitation of desperate couples. The GPPC survey concurrent with the report showed that 61% of Americans responding approved of tissue typing, while 80% expressed the concern that 'if not regulated, reproductive genetics could 'get out of control''[83].

Given that the report of the public consultation on PGD in the UK expressly stated that no permission for HLA typing could be given without further discussion because of the ethical issues it raised[84], it was surprising that in the same month as the report's publication, November 2001, the HFEA, with no further public discussion or consultation on the matter, gave permission for tissue typing when PGD was already

---

[76] ESHRE PGD Consortium Data Collection III, p.242.
[77] H. Van de Velde, I. Georgiou, M. De Rycke et al., 'Novel Universal Approach for Preimplantation Genetic Diagnosis of B-thalassaemia in Combination with HLA Matching of Embryos', *Human Reproduction*, 19 (2004) 700-708.
[78] Verlinsky et al., 'Preimplantation HLA Testing', p.2084.
[79] Infertility Treatment Authority, 'Tissue Typing In Conjunction with Preimplantation Genetic Diagnosis', <http://www.ita.org.au/_documents/policies/Policy_PGD_HLA_matching.pdf> [accessed 15 March 2004]
[80] Naoki Takeshita and Harumi Kubo, 'Regulating Preimplantation Genetic Diagnosis: How to Control PGD', *Journal of Assisted Reproduction and Genetics*, 21 (2004) 19-25 (p.19).
[81] Robertson, et al., 'Conception to Obtain Hematopoietic Stem Cells', p.38.
[82] 'Preimplantation Genetic Diagnosis: A Discussion of Challenges, Concerns, and Preliminary Policy Options Related to the Genetic Testing of Human Embryos', (Baltimore: Genetics and Public Policy Center, 2004).
[83] *American Society of Reproductive Medicine Bulletin*, 6, 27, 6 May 2004 <http://www.asrm.org/Washington/Bulletins/vol6no27.html> [accessed 25 August 2004]
[84] HFEA/HGC, Outcome, p. 6, para 29.

being done. In addition the HFE Act makes no comment about tissue typing, as this procedure was not envisaged when the Act was passed in 1990.

In December 2002, the permission to tissue type granted by the HFEA to the Hashmi family was successfully challenged and reversed in the UK High Court by the campaigning group Comment on Reproductive Ethics (CORE) which takes a conservative 'pro-life' stance regarding embryo status and use. After examination of the provisions of the UK's Human Fertilisation and Embryology Act of 1990 (HFE Act), the judgement given expressed the view that tissue typing could not 'be said to be 'necessary or desirable' for the purpose of assisting a woman to carry a child', adding that 'the language of the Act does not bear the strain which would be necessary to read 'with particular characteristics' into the carrying of the child'[85].

Nevertheless, the HFEA brought the case back to the Court of Appeal in April 2003 and this court unanimously reversed the High Court's decision, ruling instead that the HFEA *did* have the power to authorise tissue typing[86]. Brownsword has cogently questioned this Court of Appeal decision arguing that the purposes of tissue typing represent a fresh dimension not covered by the HFE Act[87]. One of the Appeal Court judges, Lord Philipps, asserted that helping women to enjoy a confident pregnancy means they should be assisted to have children with 'desired characteristics' relating not only to the child's health but also its suitability to be a tissue donor[88]. Brownsword rightly describes this as 'quite extraordinary'[89]. He considers Lord Phillips' wording about the child's suitability for the woman's purpose 'smacks very strongly of consumers needing assurance about the suitability about goods (or services) and their fitness for purpose'[90]. I agree with Brownsword that such an approach sounds dangerously like commodification[91]. He concludes that the decision about tissue typing should not have been returned to the HFEA[92]. At the time of writing CORE have now taken the case to the House of Lords and a further decision is awaited.

Given this considerable confusion about whether British law as it stands allows the HFEA to give permission to tissue type, it seems obvious that the law should be revisited so that it speaks with clarity on this issue. The HFEA has signalled its openness to such a review[93]. It would certainly provide a way of ensuring that tissue typing becomes the single acceptable means by which embryos may be selected legally on the basis of a genetic trait unrelated to disease. It is to be hoped that Parliament enacts such legislation as soon as possible.

---

[85] Quintavalle V HFEA, Judgment by Mr Justice Maurice Kay, para. 17.
[86] Brownsword, p. 306.
[87] Brownsword, p. 313.
[88] Brownsword, p. 309.
[89] Brownsword, p. 318.
[90] Brownsword, p. 318.
[91] Brownsword, p. 319.
[92] Brownsword, p. 319-320.
[93] HFEA, 'Evidence for The Science and Technology Select Committee: Inquiry on Human Reproductive Technologies and the Law', May 2004, para. 7, p.3.

Avoiding the exploitation of desperate couples.

Any legislation concerning tissue typing should also include the protection of couples whose desperation to save a sick child may leave them open to exploitation. Winston and Hardy have expressed their concerns about the combination of 'patient desperation, medical hubris and commercial pressures' leading to less than ethical decision making about the use of reproductive technology'[94].

In view of the lack of long-term evidence of the safety of PGD on child development and also of the desperate situation faced by parents requesting tissue typing to try and save an ailing sibling, it is clear that accurate and transparent information and counselling for parents is vital regarding (a) the risks of biopsy damage or misdiagnosis in PGD and tissue typing and (b) the physical, emotional and financial cost of repeated cycles of treatment with low likelihood of success. Regarding the latter, in about one third of all PGD cases only one embryo is diagnosed as suitable for transfer[95]. This makes repeated IVF cycles more likely even when PGD is used solely to avoid disease. This situation is greatly exacerbated when performing tissue typing as it reduces further, by on average 75%, the number of embryos considered for transfer. A case in point is that of the Hashmi family. Sadly, in July 2004 it was reported that after six cycles of IVF costing £60,000 had failed to result in a live birth, the Hashmis had taken doctors' advice that it was unwise to continue because of adverse effects on Mrs Hashmi[96].

An obvious conclusion is that couples will need comprehensive professional support and advice about the heavy physical and mental demands of undergoing repeated IVF cycles when both PGD and tissue typing are attempted.

Conclusions.

Six significant conclusions can be drawn from the above discussions:

1. A case can be made that tissue typing itself would not involve unacceptable commodification, instrumentality or psychological damage to the resulting child. Central to this case is the reactive rather than proactive nature of the parents' request for embryo selection, which is borne of medical necessity and the compassionate parental desire to heal a seriously ill child rather than a parental urge to specify a child's characteristics. A case has also been put against extending tissue typing to assisting other than a seriously ill sibling.

2. Questions remain about the safety of PGD, so that careful attention must be given to the results of a long-term study on risks from PGD to child development.

3. If a long-term safety study verifies that the risk of damage from biopsy is within acceptable limits, this confirms that the case can be made to allow families like the Whitakers also to do tissue typing, as in their cases the procedure involves less risk of the other possible drawback – misdiagnosis – than in cases like that of the Hashmis, where PGD is required in addition to tissue typing.

---

[94] Winston and Hardy, p. S17.

[95] HFEA/ACGT, Document on Preimplantation Genetic Diagnosis, <http://www.hfea.gov.uk/pgd/pgdpaper.pdf> [accessed January 2000] para.16, p5.

[96] 'Hashmis Fail in Designer Baby Cure for Son', *ITV Yorkshire*, 4 July 2004. <http://www.itvregions.com/news.php?region=Yorkshire&content=7683&cat=0> [accessed 14 July 2004]

4. If a long-term safety study suggests that there is an unacceptable risk of damage from biopsy or of misdiagnosis, the law on the use of PGD (either for tissue typing or for the avoidance of disease) needs to be redrawn accordingly.

5. Parents urgently seeking tissue typing to help an ailing sibling need careful protection from exploitation of their desperation. This suggests access to independent but informed counselling about the wisdom of continuing with further stressful and expensive cycles of treatment and about the risks involved from biopsy and misdiagnosis.

6. Specific legislation concerning tissue typing is necessary as it is questionable whether it should be allowed under the present UK law. Taking a view of the moral status of the embryo that requires the minimising of embryo selection also entails arguing that the law must reinforce the HFEA's stated view that tissue typing is only ever to be used as a 'last resort' procedure. Furthermore, without legislation it will not be possible to preserve HLA type as the only genetic trait unrelated to disease for which it is allowable to test or on the basis of which it is legal to select embryos.