

# Ethics briefings

## Born to be a donor?

When children have a life threatening illness, parents are often prepared to consider any measure that could save them. Having another child who could donate bone marrow or other cells may be a lifesaver. In December 2001 the UK Human Fertilisation and Embryology Authority (HFEA) decided in principle to allow HLA (human leukocyte antigen) typing to be used with preimplantation genetic diagnosis (PGD) for serious genetic disease. Parents at risk of transmitting genetic diseases could use PGD, not only to select embryos free of disease, but also to choose those with the best tissue match to the dying sibling. The HFEA's agreement to selection by HLA typing was subject to strict conditions<sup>1</sup> and each individual request must be considered by the HFEA. In the following months, the HFEA considered two applications, it approved one and the other (for a non-genetic condition) it rejected. Interestingly, both decisions attracted criticism, the first for being too liberal and the second for being too conservative.

The first case concerned Zain Hashmi who had beta thalassaemia. His parents wanted PGD to avoid the birth of another affected child and also to select embryos most likely to produce a baby who would be a compatible donor. They hoped to use stem cells from the umbilical cord blood to produce bone marrow for the transplant, thus the future child would not undergo any invasive, painful, or risky procedures. Approval was given by the HFEA for this case. In the second case, Charlie Whittaker had Diamond-Blackfan Anaemia (DBA), a rare life threatening blood disorder. Although some children with DBA inherit this condition from carrier parents, his parents were not actually carriers. Pre-implantation genetic diagnosis was not needed, therefore, to avoid the birth of an affected child but the couple wanted it solely to provide a compatible donor for Charlie. As with the Hashmi case, stem cells would be taken from the umbilical cord blood.

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The HFEA rejected this application because the PGD was not intended to avoid a serious disorder in the future child. Thus, it failed to meet the HFEA's criterion requiring that: "the embryos conceived in the course of this treatment should themselves be at risk from the condition by which the existing child is affected".<sup>1</sup>

### Welfare of the child

A key concern in both cases was the possibility of psychological harm to the child who would be selected and born to be a donor. Although likely to be as loved as any other, might the child resent being "selected", and feel less wanted or less respected as an individual? Might the child be proud of being uniquely able to save a life or feel obliged to donate bone marrow if pain free treatment with cord blood failed? Would the parent-child relationship be affected if both failed and the sibling died? It is, of course, impossible to predict. Yet these hypothetical risks of harm have to be balanced against the real harm of death for the sibling without donation. Refused PGD, parents may continue to have children naturally in the hope of obtaining a match; the harm to those children, particularly if they are unsuitable as donors, needs also be considered.

It is frequently argued that if such selection were permitted, children would be born as a means to someone else's ends rather than for their own sake. In reality, however, parents have children for many reasons to do with their own wishes and desires. Also, as Gillon points out in another context<sup>2</sup> it is not unusual for individuals to use each other as a means to an end. In helping each other, we do not become *merely* a tool for achieving objectives. If donor children were abandoned after the treatment they would have been merely tools. In practice, this is most unlikely. Nevertheless, such concerns need to be taken seriously in this debate. For those who believe that the risks to the selected child override all other considerations, neither of the cases described above would be acceptable. But, are there reasonable grounds for differentiating between them as the HFEA does?

### The use of human embryos

The HFEA judged there to be a fundamental difference between cases

where the invasive procedure (PGD) was undertaken for the benefit of the embryos themselves—that is, to select those free of the disorder, and where it was being carried out solely for the benefit of others. An undeniable practical difference exists in the two scenarios, but does this constitute a moral distinction? This needs to be considered in the societal context of the status accorded to the embryo. In the UK, human embryos may be used for research to pursue questions important to the public good. If they are used to improve fertility treatment and contraceptive measures, is it appropriate to prohibit their use to save a child's life? Or is there a difference between embryos which will be replaced and may become a child and surplus embryos that will otherwise be destroyed? After nearly 20 years of such debate in the UK, new and perplexing questions still arise about where limits should be set.

## Review of the law on organ donation and retention

Following the organ retention scandals at Alder Hey and elsewhere<sup>3</sup> the UK is undertaking a thorough review of the legislation governing organ donation and retention of material following postmortem examination. A major consultation exercise has been undertaken in England and Wales<sup>4</sup> looking at these and other broader issues (such as storage of gametes and the use of fetal tissue in research). In Scotland, however, it is proposed to address questions of organ retention and organ donation separately.<sup>5</sup> A main advantage of the Scottish approach is that it avoids the risk that pejorative views about organ retention might negatively affect transplantation rates when moves are afoot to improve transplantation. For England and Wales, however, the practical difficulty of gaining parliamentary time for debate means that transplantation is likely to lose out if, as is likely, time is made for only one bill. Given the option of a combined bill or no bill, most of those who wish to see improvements in transplantation opt for the former. Given the acknowledged importance of having uniform legislation on this type of issue across the

UK, it will be interesting to see how this apparent conflict is resolved.

Between July and October 2002 a separate consultation in England and Wales centred on a draft code of practice for the import and export of body parts.<sup>6</sup>

## New UN rapporteur on right to health

Various facets of the international debate about the “right to health” or the “right to treatment” have featured previously in these briefings.<sup>7</sup> Since 1996, the British Medical Association (BMA) and a network of medical human rights groups have campaigned for the establishment of a new thematic rapporteur at the United Nations whose role would include:

- monitoring health professionals working where human rights are threatened;
- supporting health professionals at risk of attack for their professional activities, and
- encouraging health professionals to report evidence of human rights violations.

The issue moved on in May 2002 when the United Nations Commission for Human Rights agreed to the creation of a new special rapporteur on the right to health. In August, Paul Hunt of Essex University’s Human Rights Centre was appointed as the first post holder. The post is likely to include responsibilities to oversee the implementation of the “right to health” and monitoring of the provision of care without discrimination. Thus, the rapporteur’s role will reflect much recent UN debate about how the so called “right to health” should be defined in

practical terms, according to standardised international benchmarks.<sup>8</sup> It is also likely to include analysis of the practical obstacles to ethical behaviour in conflict situations and to provide support for health professionals who attempt to treat patients without discrimination. Actions such as the targeting of ambulances and health workers in armed conflicts may come within the rapporteur’s remit. In Kosovo in 1999, for example, doctors treating Albanians were particularly targeted by Serb forces<sup>9</sup> and following the Gujarat massacres of Muslims in Spring 2002, Hindu doctors were warned not to attempt to treat Muslims and ambulances were attacked.<sup>10</sup> In July 2002, debate at the BMA’s annual meeting particularly highlighted impediments to the provision of health care to Palestinians in the context of the Israeli-Palestinian conflict. It can be seen, therefore, that the new rapporteur faces some very difficult problems in the international arena.

## Euthanasia in Belgium

In May 2002, Belgium’s Chamber of Representatives backed the senate’s earlier vote in favour of euthanasia, making it the second European country to introduce a clear statute permitting euthanasia.<sup>11</sup> Patients who have incurable and unbearable suffering may request euthanasia, which will be carried out no less than one month later if certain conditions are met. The law also allows a patient to express a desire for euthanasia in a living will. Provided the same strict conditions that apply to competent patients are

met, doctors may perform euthanasia on an incompetent patient who requested it in a living will.

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## References

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- 2 **Gillon R.** Human reproductive cloning—a look at the arguments against it and a rejection of most of them. *Journal of the Royal Society of Medicine* 1992;**92**:3–12.
- 3 **English V, Gardner J, Romano-Critchley G, et al.** Organ retention. *Journal of Medical Ethics* 2001;**27**:135–6.
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- 7 **English V, Gardner J, Romano-Critchley G, et al.** International debate about the “right to health”. *Journal of Medical Ethics* 2000;**26**:473–4; **English V, Romano-Critchley G, Sommerville A.** A right to treatment? *Journal of Medical Ethics* 2001;**27**:413–14.
- 8 **See reference 7.**
- 9 **British Medical Association.** *The medical profession & human rights.* London: Zed Books, 2001: ch 10.
- 10 **Docs told to stay off minority areas.** Quoted in: Centre of Enquiry into Health and Allieith Themes (CEHAT). *Genocide in Gujarat 2002: impact on health and women.* Mumbai: CEHAT, 2002. Sharma R. Ambulances attacked by mobs in Gujarat. *Times of India* 2002 May 8.
- 11 **Chambre des Représentants de Belgique.** *Project de loi relatif à l’euthanasie.* Doc 50 1488/001. Brussels: Chambre des Représentants de Belgique, 2002. An unofficial translation of the law into English is available at [www.worldtrtd.org/BelgiumLawTransl.html](http://www.worldtrtd.org/BelgiumLawTransl.html)