

EDITORIALS

The Lords' Report on Stem Cells *Selective with the truth*

There is no doubt that stem cell technology holds great promise for sufferers of degenerative conditions like diabetes, Alzheimer's and Parkinson's disease, but the main issue addressed by the Lords' Select Committee on Stem Cell Research was whether research on cloned human embryos was still necessary, given recent advances in the ethically acceptable alternative use of adult stem cells.

The Donaldson report, tabled in June 2000, on which the newly passed law is based, took what the Lords now acknowledge to be an overly pessimistic view of the properties of adult stem cells. Two years is a long time in science, and subsequent research has confirmed their amazing versatility in treating a wide variety of conditions in both humans and other mammals (www.stemcellresearch.org)

The very latest research from the University of Minnesota (reported in the *New Scientist*, 23 January) reports discovery of a new variety of adult stem cell (dubbed the multipotent adult progenitor cell or MAPC) which is easy to isolate and culture, and has been shown, given the right conditions, to have the same versatility as the embryo stem cell, but without the risks of immune rejection, uncontrolled growth or cancer.

Given the considerable technical and ethical problems of cloning human embryos, growing international opposition to the practice and the danger that reproductive cloning will follow, it is outrageous that the Lords' committee have not only authorised it, but have misled the British public, and especially vulnerable patient groups, into believing that their best hope lies in this direction.

Goldenhar Syndrome

A tragic breakdown in communication

A high profile disagreement between doctors and the parents of a baby with a rare facial disorder was finally resolved after a seven hour High Court hearing in Leeds, when the parents agreed to an urgent tracheotomy (*BBC News*, 7 March).

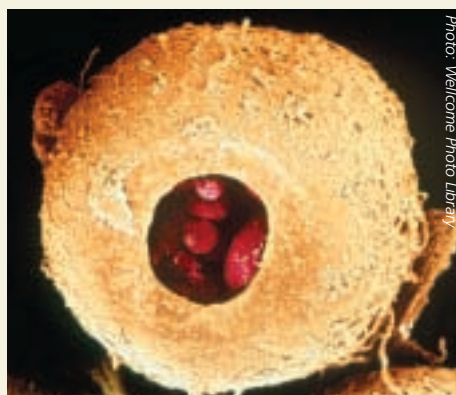
Twelve week old Maria Aziz Al-Rafi, the only survivor of triplets born in Saudi Arabia, has oculoauriculovertebral dysplasia (Goldenhar syndrome), a rare condition affecting only one in 500,000 babies, and has no right eye or ear, and only half a nose and jaw. She will require 18 years of surgery to correct abnormalities, and doctors at Royal Victoria Infirmary in Newcastle-upon-Tyne had wanted to perform a preliminary tracheotomy to secure her airway and assess the anatomy.

But the parents, who had already started a public appeal to raise £500,000 for private reconstructive surgery in the US, threatened to withdraw their child from the intensive care ward after the mother clashed with a consultant over proposed treatment. They were worried about losing their daughter during surgery, and also about 'medical staff experimenting and trying different procedures'.

Lord Fenwick, of the Newcastle Hospitals Trust, in taking the case to court said, 'The hospital was obligated to act in the best interest of the child'.

Legally, the balance of power over a child is weighted in the parents' favour, on the assumption that parents will look after a child better than the State. But these rights do not extend to letting a child die or suffer by refusing necessary medical treatment.

But it is tragic that what began as a breakdown of communication between doctors and parents should escalate into a full-blown media circus and court proceeding. It is a reminder that good medicine involves far more than technical expertise. It is as much about understanding anxieties, addressing fears, patiently answering questions and giving information, and communicating empathy in a way that gains trust. The doctor/patient relationship, is a relationship, not a contract.



Human embryo perforated for harvest of cell for genetic testing.

HFEA Decision on Designer babies *An unethical and dangerous precedent*

A Leeds couple, Shahana and Raj Hashmi, have been given permission to create a baby to act as a bone marrow donor for their son Zain, who suffers from thalassemia. No compatible donor has been found. The couple will undergo IVF treatment with the resulting embryos being screened for both thalassemia

and tissue compatibility. Any resulting baby will donate umbilical stem cells after birth.

In defending the judgement, Michael Nazir Ali, Bishop of Rochester, who chairs the Human Fertilisation and Embryology Authority's ethics committee said, 'We are minimising harm and maximising good...this is not a liberty hall for the child to be created as some sort of spare parts factory'.

The use of umbilical cord stem cells in bone marrow transplants is an exciting scientific advance, which if successful, offers the chance of a cure for otherwise fatal inherited blood disorders, with minimal risk to the donor.

But in allowing preimplantation diagnosis and embryo selection in order to ensure the birth of tissue-matched donor babies, the HFEA have set an unethical and dangerous precedent.

It is unethical because the approved procedure involves destroying embryos that fail to fulfil the selection criteria. Whilst it is true that in very rare circumstances, the only way of ensuring that a tissue-matched donor is born, is to use this kind of 'search and destroy' technology, the end of saving a human life never justifies such means. This ruling moves the goalposts even further than before as embryos, which are of the wrong tissue type, but otherwise normal, are to be discarded in order to treat a condition which is not necessarily fatal.

The precedent is also dangerous because, despite the HFEA's assurance that the procedure will be used only in 'very rare circumstances and under strict controls', the ruling is likely to lead to a slippery slope whereby designer embryos and fetuses can be created and destroyed for more and more trivial reasons. It also cannot be in the best interests of any donor child, however much they are subsequently loved, to be created for the primary purpose of providing transplant material for somebody else. And if the umbilical cord transplant fails to work, for whatever reason, then pressure may well be on the resulting child to provide stem cells via more invasive harvesting procedures.

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