

# Eggs and Sperms and Rock'n'Roll

## Britain's HFEA has to Juggle Delicate Bioethics Issues

**B**ioethical questions surrounding human reproduction, embryos, and stem cells make front page news nearly every week. In February, it was the cloning of human embryos for the purpose of producing stem cells (therapeutic cloning). Before that we saw discussions about anonymity of sperm donors, sex selection, cloning claims from maverick scientists, IVF mix-ups, "designer" babies, etc. By the time you read this, half a dozen other stories of this kind will have appeared, complete with screaming tabloid headlines about "scientists playing God".

### Embryo Sitters

These and similar issues affect most European countries in some way, although each has its own potentially explosive mixture of science, religion and politics. The UK is relatively lucky in that an authority to deal with these issues was already in place before they started to boil over. The Human Fertilisation and Embryology Authority (HFEA, [www.hfea.gov.uk](http://www.hfea.gov.uk)) was set up in August 1991, as required by a law passed the previous year. Its main tasks were to

- license and monitor IVF clinics
- license and monitor research on human embryos
- regulate the storage of gametes and embryos

In addition, it also has advisory roles to the government and to patients. While this brief must have looked innocent enough in 1991, it has since then grown to include a huge range of extremely sensitive bioethics issues.

The HFEA, based in East London near Liverpool Street Station, is both an authority consisting of members that meet once a month, and a government department staffed with civil servants and equipped with a budget of around two million pounds. The authority board acts as a supervisory board to the department structure. Ruth Deech, a law professor and warden of St. Anne's College at Oxford, chaired the authority from its foundation through to the spring of 2002. Her successor is Suzi Leather who has a background in political science and consumer issues. She was the deputy chair of the Food Standards Agency from 2000 to 2002.

### "Designer" Babies

One of the biggest moral dilemmas facing the authority over the last few years was

the saga of the permission to select embryos for implantation that might become life savers for their siblings. On a background of misrepresentation by the media, who coined the word "designer baby" even though there never was any creative design process involved, the authority ruled that the selection of an embryo based on pre-implantation genetic diagnosis (PGD) was allowed in the case where it helps to ensure the child resulting from the treatment would be free of inherited disease. If, in addition to being healthy, it would also be able to provide umbilical cord stem cells that help to cure a sibling, even better. In contrast, the authority denied parents permission to use PGD solely for the benefit of the suffering sibling in cases where the new baby would not be at risk of genetic disease.

On these grounds, the authority refused permission for the family of little Charlie Whittaker to produce a tissue-matched sibling by PGD (which did not stop them, however, from having the procedure carried out in the United States). On the other hand, the HFEA approved the application from the family of Zain Hashmi. As Zain's blood disorder, beta thalassaemia, is genetic, PGD would not only help to produce a tissue-matched sibling but also ensure that the new baby would be free of the disease.

Public trust in the Authority's authority was badly shaken in December 2002, when the High Court ruled that the HFEA had no right to grant the Hashmis this permission. In April 2003, however, the Court of Appeal toppled that decision and ensured the Hashmis would be free to proceed regardless of the outcome of any further legal action. Currently, all such cases have to be decided by an HFEA committee on an individual basis, following the stringent criteria mentioned above.

### Stem Cells

In its role of supervising embryo research, the HFEA is also in charge of deciding who is allowed to produce human embryonic stem cells in the UK. So far it has only granted three licences to generate new stem cell lines: One went to King's College, London, where the group of Stephen Minger last year successfully produced the first human ES cell line in the UK. The most recent licence was granted in June 2003 to the Roslin institute near Edinburgh, famous for the cloning of Dolly the sheep.

The HFEA also has to stay on top of all bioethics news, even when they come from abroad. Thus, when Korean scientists announced their breakthrough in generating a new stem cell line from a cloned human blastocyst, the authority immediately issued a press release welcoming the progress. In marked contrast to official reactions from the US, Suzi Leather referred to it as "an important area of medical research" and emphasized that this kind of research would be legal in the UK too (subject to a licence granted by the HFEA). In a bid to mark the boundaries, she also affirmed that any attempts at reproductive cloning would be illegal in the UK.

### Keeping up with the Red Queen

While the early arrival of the HFEA on the bioethics scene means that it already had an established structure and reputation by the time things got complicated, it also means that the 1990 parliament act on which it is based could not possibly foresee most of the problems the authority is now faced with. At the HFEA's annual conference in January, chairwoman Suzi Leather launched a review of the old law, saying it had become "anachronistic" in places. For instance, she addressed the law's requirement for the IVF doctors to attend to the "need of a child for a father" before proceeding. The authority's review of the law is due to be presented to the government by the end of this year, but it looks likely that consultations will be held in 2005, so it may be some time before a new law could be passed. Like Alice racing the Red Queen, legislators have to run faster and faster to keep up with changes in the field of fertility and embryo research. In the absence of any perfect solution to this fundamental problem of fast-moving technologies, the HFEA, with its reputation for balanced decisions looks like a really useful thing to have.

### Michael Gross

He is a science writer in residence at the school of crystallography, Birkbeck College, University of London. He can be contacted via his web page at



[www.proseandpassion.com](http://www.proseandpassion.com)