



Mavericks and miracles

Time for a global ban on human cloning

The weekend claims by a bizarre American cult to have produced the world's first human clone - with another four babies due before the end of January have yet to be verified. But if the cult fails, others will succeed unless government intervenes. Serious medical scientists are right to feel threatened by the sick global race among maverick scientists striving to become the first to produce a human clone. Compare and contrast the two different scientific groups. It is only just over a year ago that serious scientists in America announced the first cloned human embryo. This was a time for rejoicing. Although the embryo clones were produced using a similar technique to the one that created Dolly the sheep, the purpose was not reproductive, but therapeutic.

The medical breakthrough offered millions of people suffering from chronic or degenerative diseases hope of release from their pain and misery. Earlier in the year, the UK's parliament rightly approved such research. This followed a detailed report from an expert committee and wide consultation organised by the human fertilisation and embryology authority. Both exercises ended in unequivocal support for further stem-

cell research. Embryonic stem-cells, unlike adult stem-cells, possess the ability to develop into different types of tissue in the body - offering new hope to people suffering from wasting and incurable diseases such as muscular dystrophy, congestive heart disease and Alzheimer's. The early stage embryos are all under 14 days old, smaller than a pinhead, with no recognisable human feature. Compare this research with the work of the mavericks. In the words of Dr Patrick Dixon, a medical ethicist, cloned babies would face "a living nightmare with a high risk of malformation, illhealth, early death and unimaginably severe emotional pressure".

Most cloned animals have genetic or congenital abnormalities. Even those not born with deformities often develop them later. The birth of just a few badly deformed babies could provoke a public backlash against all embryo research stalling vital medical advances. Cloned babies could also provide the opportunity to pursue dangerous eugenic policies. France and Germany have already submitted a convention to the United Nations banning human cloning. The US has recently signalled its support. It is time it was endorsed by all.

A Present for Anna

Creating Bioethical Awareness through Interactive Theatre

STRUCTURE OF PROJECT

PRE-VISIT – 25 mins

VISIT BY THE TEAM – 120 mins

POST-VISIT – 60 mins

PRE-VISIT

COMPOUND STIMULUS

Aims to "hook" students on storyline & to signal something of the "problem" and people involved.

Guideline from HFEA

Precis of HFEA code of practice

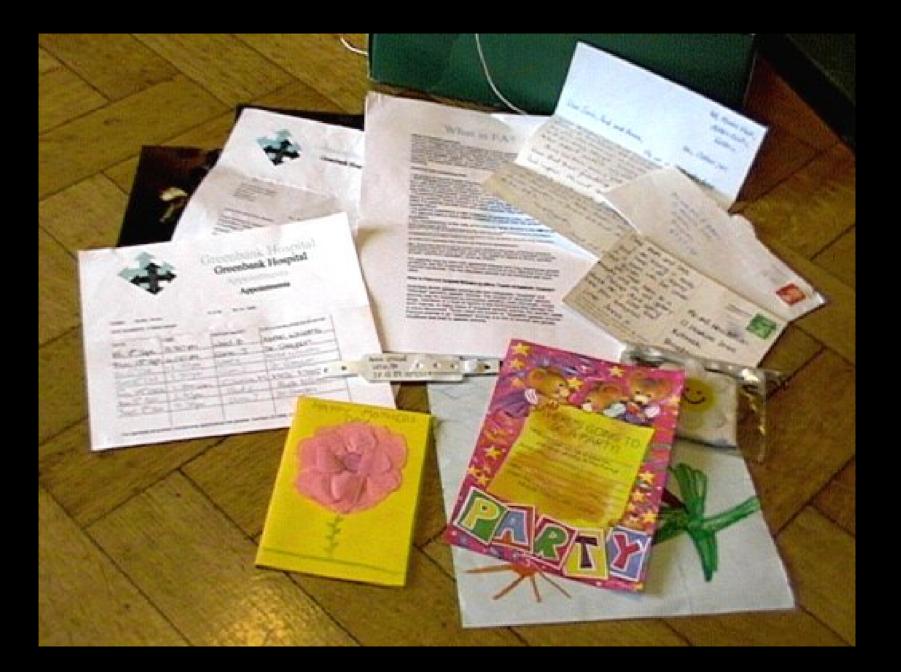
Letter of invitation to discussion group













Human Fertilisation & Embryology Authority Greenway House, 42 Bishop Street London E4 6LP Reference: 243303 CERTIFIED MAIL

20/11/01

Dear Sir/Madam.

Subject: Draft Regulation

I am writing in order to invite you and your colleagues to a public consultation regarding the draft regulation, of which you will shortly receive a copy. As you will already be aware, the Human Fertilisation and Embryology Authority frequently seeks the advice of public groups (such as Theologians, Sociologists, Biologists) before introducing changes to the Code of Practice.

I would be most grateful if you were able to attend a meeting with your fellow group members on Thursday 29th November. I apologise for the late notice, but this matter has been brought to our attention as one of some urgency, although the HFEA does not allow 'knee jerk' reactions to individual cases, this is a delicate and sensitive matter which must be decided upon immediately.

We greatly value the presence of a group of your expertise at this public consultation, as we aim to comprehend the opinions and advice of a large cross section of society before considering new policies. I hope to see you next week.

Sincerely yours,

Professor A.Rogerson Chairperson HFEA Human Fertilisation & Embryology Authority Enclosure (1) AAJ

Précis of HFEA Code of Practice Regulations Relevant to the Meeting on 29.11.01

- 3.1 Centres should take all reasonable steps to ensure that people seeking treatment and any child resulting from it have the best possible protection from harm to their health. Before providing any woman with treatment, centres must also take account of the welfare of any child who may be born or who may be affected as a result of the treatment.
- 3.2 Centres should therefore ensure that the medical needs of the people seeking treatment are fully assessed, and that any treatment offered is the most suitable to meet their needs.
- 3.3 In addition, in deciding whether or not to offer treatment, centres should take account both of the wishes and needs of the people seeking treatment and of the needs of any children who may be involved. Neither consideration is paramount over the other and the subject should be approached with great care and sensitivity. Centres should avoid adopting any policy or criteria that may appear to pressurise either party.
- 3.8 One of the conditions of a treatment licence being issued to a centre, is that "a woman shall not be provided with treatment services unless account has been taken of the welfare of any child who may be born as a result of the treatment, and of any child who may be affected by the birth" HFE Act 1990 section 13 (5). "Any other child" includes children who already exist within the woman's household or family.
- 3.10 Centres should have clear written procedures to follow for assessing the welfare of the potential child and of any other child who may be affected. The HFE Act does not exclude any category of woman from being considered for treatment. Centres should take note in their procedures of the importance of a stable and supportive environment for any child produced as a result of treatment.
- 3.13 Where people seek treatment, centres should bear in mind the following factors:
 - a. their commitment to having and bringing up a child or children;
 - their ability to provide a stable and supportive environment for any child produced as a result of treatment;
 - c. their medical histories and the medical histories of their families;
 - d. their health and consequent future ability to look after or provide for a child's needs;
 - e. their ages and likely future ability to look after or provide for a child's needs:
 - f. any risk of harm to the child who may be born, including the risk of inherited disorders or transmissible diseases, problems during pregnancy and of neglect or abuse; and
 - g. the effect of a new baby upon the existing child of the family.
- 3.15 Where it is the intention that the child will not be brought up by the carrying mother, centres should consider the factors listed in 3.13 as applicable to all those

Preliminary Draft of Proposed New Regulation

Subject: PGD (Preimplantation Genetic Diagnosis)

Currently, 'PGD is a technique whereby embryos created outside the body can be tested to see whether they carry a genetic disorder before being transferred to the uterus'. * This technique has been applied since the 1980s, in order to identify gene and chromosome defects at the embryonic stage of development. Using PGD, embryos are biopsied and screened to identify any carrying the genetic disease (e.g. haemophilia, Huntingdon's disease, Fanconi Anaemia). The disease free embryos are then implanted using IVF (in vitro fertilisation). This process is often seen as preferable to PND (pre natal diagnosis), as it does not involve the termination of a diseased foetus.

This new regulation proposes to alter a section of the act that states that only diseased embryos are to be removed from the sample for implantation into the uterus. This section will have a clause added, stating that an immunological match to an existing sibling may be screened for. This will enable any child born following implantation to aid an existing sibling affected by congenital disease, through donation of stem cells or bone marrow etc. Also, under current UK regulation, stem cells from the embryo may be cultured in a laboratory, to aid the existing child without necessarily resulting in the birth of a sibling. The regulation, as amended, would read: prior to implantation, PGD techniques may be implemented to remove and dispose of any defective embryo or any embryos which do not exhibit the desired trait, in the case where an immunological match is being sought.

^{*} From section one of the HFEA consultation document on PGD, as stated in 2000.

VISIT BY THE TEAM

Welcome from HFEA representative

Meet Butler Family

Series of scenes -> Anna into wheelchair

Hotseating

Widen out to other case studies

Share these

Back to regulation

Decision

Tell Anna's parents





























POST-VISIT

Writing task:

One side of A4 on an aspect of ethical considerations in biomedicine

Writing Task

Please complete one side of A4, word-processed (12 font, Times New Roman) writing on the following topic:

What right do we have to intervene in natural life processes? Where are the boundaries, and who decides them?

Please give this writing to your teacher within one week of the bioethics theatre group's visit. We will be using selected passages from the writing in a book that will be given back to your school to assist with teaching and learning about ethical issues. The authorship of any extracts used will be acknowledged.

John Somers. J.W.Somers@ex.ac.uk

"I believe that we do not have the right to take another life to improve our own, but I also believe that an embryo is in the first stage of development is nothing but a cluster of cells. I believe that this is where the boundary lies: if the embryo develops the primary streak (the beginnings of the central nervous system), then perhaps it can be described as sentient."

"The religious opinion is that God is the giver and taker of life, which means that humans have no right to choose who is to live or to die at a particular point in their life, but that only the Lord knows when a person's time has come. However, some may argue that the majority of illnesses have man-made origins, and so it is up to us to fix what we have caused."

"When we talk about what gives us the right to intervene, I wonder who there is to deny us the right. It is part of human nature to want to help the people we love in any way we can. If you have to kill a bunch of cells to help that person, so be it."

"My opinion is that biotechnology should be managed in such a way that the law stops people exploiting new processes for money or self-aggrandisement. Religious issues must also be taken into consideration which will be tricky in our ever-changing, multicultural world."

"I enjoyed this way of working as it helped me to realise all of the different views and [....] it brings cases to life which you don't get from a textbook. The play was a powerful demonstration of the human emotions involved in a genetic and ethical dilemma."

"My name is Catherine, and I was the one who wouldn't shut up when you came to discuss bioethics at Exeter College. I just wanted to add to what I said to some of the others about the Catholic belief system"

(she then enters into a closely argued case for scientific restraint, linked to an analysis of 'The Crucible' by Arthur Miller.)

"As the result of the vote was presented to Mr and Mrs Butler, the room was silent. We saw the pain on their faces, we imagined their broken hearts. The guilt rushing through us like bullets! What have we done? We have just told the parents of an only child that we will not allow the possibility for her to be saved. Now they have to tell her. The shame on our faces, the invisible tears we so long to weep. Was this the right decision, or should we have followed our hearts?"

"The compound stimulus worked well. Students initially were quite chatty, but as articles were removed from the box and described, they became much more thoughtful and constructed a possible story in a serious way."

"I was surprised and delighted at the ability of the TIE team to capture the attention of my students for 2 hours and all were still fully involved at the end." "I could not fault the TIE team's scientific knowledge which surprised me as I saw them as actors and not scientists."

