



Dawn Primarolo MP,
Department of Health,
Richmond House,
79 Whitehall
London SW1A 2NS

5th December 2007

Dear Ms Primarolo,

Genetic modification of human embryos

I am writing to you to express Human Genetics Alert's opposition to the Government's plans to allow genetic modification of human embryos for research purposes. It is the first time that any country has officially sanctioned genetic engineering of human embryos as the first step towards allowing human genetic modification (HGM). We believe that you may not have fully appreciated the far-reaching consequences of such a decision. It is not clear to us why you have ignored the strong public opposition to genetic modification of human embryos which was expressed in the consultation.

There have been two suggestions about why genetic modification of human embryos should be permitted: firstly, in the consultation document, that it is necessary in order to develop the technology for the eventual creation of GM babies; secondly, in recent months the Government has emphasised the use of genetic modification in basic research. We note that the Government has not bothered to provide the clarification of its motives on this issue which was requested by the Joint Committee on the HTE Bill, preferring to simply quote from already-published documents. The purpose of this letter is therefore to ask for clarification. Please state clearly which type of research the government wishes to permit.

1. Development of HGM technology

Because of its eugenic implications, human genetic modification (HGM) has been treated in international law very similarly to human reproductive cloning. As the White Paper notes, most industrialised countries have banned it, especially in Europe. Every country that has legislated on this subject has banned it. Most importantly for the UK, the Council of Europe Convention on Biomedicine and Human Rights bans HGM, and we are sure that the Council will be very concerned about your plans to allow genetic modification of human embryos. Please explain why Britain has failed to sign the Convention.

It is important to note that these laws have been passed because of the strong ethical and social arguments against HGM, not primarily because of concerns about the safety of the technology. The worldwide concern about HGM arises because it is by far the most powerful technology for manipulating the characteristics of human beings. It thereby

raises huge concerns about eugenics and the treatment of human embryos and children as commodities.

In brief these arguments are as follows. Firstly, HGM is medically unnecessary to avoid transmission of genetic conditions, since there are many alternative ways of achieving this. There is the traditional option of remaining childless, or parents can use sperm or egg donation. If they insist on having children who are 100% genetically their own, there are the options of prenatal testing and abortion, or genetic testing of embryos created through IVF. However, only HGM can produce genetically 'enhanced' children, and that is where its real market will be

HGM is a commodification of embryos and children. Traditionally, we see human beings as inviolable, and as endowed with rights: they must be accepted as they are. HGM overthrows that basic conception, degrading human subjects into objects, to be designed like any other consumer object, according to parents' whim. Obvious consequences would be a disruption of parents' unconditional love for children. Parents who have given your child an expensive set of genes will expect them to perform according to their specifications. Cloning and HGM represent an unprecedented intent to determine and control a child's life: for the child, it would undermine their sense of free will and of their achievements. These concerns are what many people mean when they say that we should not play God with our children.

The second concern is about the eugenic effects upon our society of permitting HGM. Parents would tend to engineer children to conform to social norms, with regard to physical ability, appearance and aptitudes, even though many of those social norms are inherently oppressive. For example, disabled people have often expressed fears that free-market eugenics would reduce society's tolerance for their genetic impairments. Cosmetic surgery is already used mainly to help people make their bodies conform to sexist and ageist prejudices. Since access to such expensive technology would be on the basis of ability to pay, we could see the emergence of biologically as well as financially advantaged ruling elites.

For a more detailed exposition of these arguments please see documents on HGA's website. As noted above, the international community has decided that these ethical and social impacts are so important, that permanent bans are appropriate. Consistent with this approach, the last two EU Framework Programmes have prohibited research directed towards HGM and reproductive cloning; and the EU Directive on Protection of Biotechnological Inventions prohibits the patenting of GM or cloned embryos.

The Government's approach seems to be at variance with the international consensus. Although you have prohibited the creation of GM babies for the present, the Government has failed to state clearly that HGM is unethical, except on safety grounds, and proposes to allow scientists to begin developing techniques to overcome the safety hurdle. It would be illogical to allow research into the development of something which you intended to remain permanently illegal; we assume, for example, that the Government would not wish to allow research aimed at the development of reproductive cloning. This leads us to the conclusion that the Government's strategy is to eventually legalise HGM, once the technology is thought to be safe.

Please state clearly whether or not the Government agrees that HGM is ethically and socially unacceptable. If it does, please explain how you can justify allowing research to develop this technology.

In our view, on an issue of such huge potential consequences for the whole world and future generations, the British Government has no right to break ranks with the international consensus. Once British scientists unilaterally begin this line of development it will be very difficult to stop, and will eventually oblige the whole world to deal with the consequences. Does the government wish to go down in history as the group of people who allowed this disastrous development to begin?

2. Basic research

HGA believes that it is unnecessary to change the law to permit genetic modification for purposes of basic research at present. However, if the government's aim is really to allow basic research, rather than the development of HGM technology, then your plans carry the severe risks of inadvertently opening the door to the latter.

We note that at present there are no proposals for basic biomedical research of this kind being put forward by the scientific community. Your department, and the Academy of Medical Sciences have given examples of possible research that might be conducted using genetic modification. However, whilst it is possible to dream up such scenarios, when looked at closely, these are either impractical or could be done by alternative methods, not involving genetic modification of embryos. For example, if researchers wish to create genetically modified embryonic stem cells, it would be far easier and more accurate to genetically modify the stem cells themselves, allowing selection in culture of cells which have been genetically modified correctly, which cannot be done with embryos. Such experiments would not even come under the HFE Act and so would not require a license from the HFEA. Furthermore, attempts to genetically modify embryos would require the use of unreasonably large numbers of eggs, since, like nuclear transfer, genetic modification is highly inefficient. We suspect that these reasons explain why, although genetic modification of human embryos has been technically possible for more than 20 years, scientists have never come forward with proposals to begin such research.

We do not make these points in order to suggest that genetic modification will never be a useful research tool, but rather to point out that it is hard to justify a change in the law on the basis of speculative ideas (such as those mentioned by the AMS), rather than concrete proposals. The recent detailed debate over cytoplasmic hybrids, for example, would have been impossible without concrete research proposals to judge, and a group of scientists to defend them. It would therefore be much better to wait until there are actual proposals to be judged, before changing the law.

In response to these points, which we made in a letter to Mr. Gareth Jones, Acting Director of the Scientific Development and Bioethics Division, Mr Jones argued that if it is true that there is no need for such research, then the HFEA would reject license applications as not being 'necessary or desirable'. We are not reassured by this suggestion, since we are not aware of any instance in which the HFEA has rejected any research license application on the basis of this extremely weak criterion. Please let us know if you are aware of such a case.

It would appear to us that the government's decision to remove the ban on genetic modification of embryos has two main motivations. Firstly, it is legislatively convenient to remove the ban whilst making other changes to the law. The second, which is apparent in the White Paper's argument that there is 'no need to preclude' such research, is a general predisposition to liberalise the governance of research.

A decision to allow the use of new techniques, in the absence of any current demand for them, or concrete research proposals, (which has been referred to as 'future-proofing') will create a severe problem. The hazard is that since there are no actual proposals to discuss there will not be adequate debate over the change, and the dangers of opening this door will not be realised. Later, when highly dangerous proposals for developing the technology for reproductive human genetic modification arise, there will be no legal basis for preventing them. Legislative convenience is not an adequate reason for exposing the public to such a hazard.

In our view, 'future-proofing' is an abdication of the government's responsibility to consider the ethical and social consequences of new reproductive technologies on a case by case basis. Instead of considering the broad public interest, it would appear that the government is bowing to lobbying pressure from narrow scientific interests. The public backlash against such an attitude has been felt before, in the GM food debate. In fact, HGA has been contacted by gene therapists who are concerned that allowing genetic modification of human embryos will lead to a reduction in public support for their own work.

The most often used analogy for the way genetic and reproductive technologies are being developed is a runaway train, with society constantly struggling to keep up with the ethical consequences of new technologies. By simply allowing unspecified research in future, without adequate debate, the government is setting the signal lights to green all the way up the track. Given the social and ethical dangers of beginning to develop HGM, the clause prohibiting the genetic modification of embryos should not be removed until there are concrete research proposals to judge. This should be done by means of a full public and parliamentary debate, not by the inadequate debate attending the making of regulations.

In summary, your proposal to allow genetic modification of human embryos disregards public opinion and is dangerous in the extreme, since it opens the door to human genetic modification. There are strong reasons why nearly all other industrialised countries have instituted permanent bans on HGM and are therefore refusing to allow research on genetic modification of human embryos. Britain and must not break this international consensus. The White Paper provides no good arguments for taking such an enormous step.

Please provide a detailed rationale for your decision and answers to all the questions posed in this letter. We would also like an opportunity to discuss with you in person the points raised in this letter. We look forward to hearing from you.

Yours sincerely,

Dr David King
Director, Human Genetics Alert